CBR POLICY DEVELOPMENT AND IMPLEMENTATION

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Contributors

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Kennedy Akolo is Programme Manager Disability for VSO Jitolee, Programme in Kenya. His qualifications include BA (Economics and Sociology) from Kenyatta University in Nairobi. Akolo has over 13 years development work experience gained in East Africa working within the in Education, Disability and governance themes. At the VSO Jitolee, Akolo manages the disability programme; Global Education and monitoring and evaluation. He is also involved in the African Campaign for disability and HIV and AIDS. Akolo also seats on the board of The Peace Building and Development Initiatives Foundation, an organization that focuses on governance and social change.

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Mr. Angaman is presently Head of the Rehabilitation services at the Ministry of Social Welfare in Ivory Cost. He is the acting Coordinator of CBR programmes in Ivory Cost. Mr. Angaman trained as a special teacher and holds degrees in literature and in communication. Before his assignment as head of rehabilitation, Mr. Angaman worked in the Socio Education Complex of Abidjan Nord as coordinator of the programmes for integration of the street youth.

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Marieke is a rehabilitation consultant with Light for the World, based in Ethiopia. She is a physiotherapist by profession and has been working with the University of Gondar (North Ethiopia) to establish the first BSc in Physiotherapy in the country and she has started a CBR program connected to the University. She is a trainer and advisor on programme development of CBR programs in collaboration with the National CBR Network in Ethiopia as well

as for individual CBR projects in-and outside of the country. In addition, she is currently a student of the Masters of Medical Anthropology and Sociology at the University of Amsterdam, where she started her study on violence against children with a disability.

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Hendrietta is visually impaired, married with three daughters and an activist on disability rights, gender, HIV & AIDS, children and youth. She is also a policy analyst and developer, a trainer, business woman, consultant, researcher on disability, development and HIV and AIDS and a writer on disability. She joined the South African Parliament at the National Assembly as Member of Parliament in June 1999 to 2004. She was appointed as Chairperson of the Parliamentary Joint Monitoring Committee on the Improvement of Quality of Life and Status of Youth Children and Disabled Persons. Hendrietta also serves on the South African National Aids council representing the disability sector. She was employed by Disabled People South Africa (DPSA) as the National Coordinator Disabled women's Development Programme (DWDP) and is a consultant for the television series Soul City.

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Rozenn is the Rehabilitation Advisor for West and Central Africa for the NGO Handicap International. After 3 years living in Burkina Faso, she now lives in Togo. As an Occupational Therapist in France she has worked for 13 years with persons with physical and mental disabilities. She also managed rehabilitation teams in public hospitals before working in West Africa. Currently, she advises about 15 project managers/coordinators in 6 countries: Mali, Sierra Leone, Liberia, Cap-Vert, Togo, Burkina Faso. She also works with Niger, Benin, Senegal, Ivory Coast. The projects she advises are in the field of CBR, P&O, physiotherapy, speech therapy, and wheelchair production.

PAUL CHAPPELL

Paul has a spinal injury following a motor vehicle accident whilst working in the Democratic Republic of Congo. After completing his MSc in Community Disability Studies at the Centre for International Development (CIDH) in London, he took up a position of CBR Trainer at CREATE in South Africa where he has been a volunteer for the past 4 years. During this time he has been involved in the curriculum design and training of mid-level rehabilitation workers, as well as research into the impact of CBR in South Africa. He is also involved in carrying out disability awareness amongst established local HIV/AIDS organisations and is currently undertaking his PhD looking at the construction of sexual identity amongst youth with disabilities in rural South Africa.

HUIB CORNIELJE

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

MIKE DAVIES

Mike Davies is CBM's Regional Director for South-East Asia & Pacific, based in Manila, and is responsible for technical and financial support to a network of 94 programmes in ten countries. He is a former coordinator for CBM's Advisory Group on CBR, and a current member of CBM's Advisory Group on Community Mental Health. A social worker by profession, Mike has been working in the disability and development field since 1968, in Africa and Asia. Before joining CBM in 1993, he was a Chief Technical Adviser in Vocational Rehabilitation with the International Labour Organisation (ILO), and before that was Director of Rehabilitation Services in Zimbabwe. He has been centrally involved in the development of the global CBR Guidelines and the launch of the Global Forum for Community Mental Health. Mike was awarded the OBE by Queen Elizabeth in 2006 for his 35 years of work with people with disabilities.

ANDREW KUDAKWASHE DUBE

I have worked with international and grassroots community organisations and completed assignments in a number of countries, including Ethiopia, Tanzania, Rwanda, Cameroon, and Senegal on behalf of the Africa Decade of Disabled People Secretariat. I completed strategic planning assignments in Swaziland and Namibia for the disability sector and government. I have experience working closely with government departments in the Southern African region at policy planning level. I won tenders to design the provincial disability strategies in the North West and Eastern Cape provinces of South Africa; and in Swaziland and Namibia.

SERVIOUS DUBE

Servious is a Senior Programme Manager for Africa with Leonard

Cheshire Disability based at the central office in London, UK. He is responsible for planning, supervision, monitoring and evaluation of regional disability and development programmes in Southern Africa, East and North Africa and West Africa. His professional training background is in 'Public Health' in Zimbabwe and he later studied for a post graduate qualification in 'Disability and Development' in the UK. He formally, worked as a 'Public Health' Officer with the Ministry of Health in Zimbabwe and later joined the NGO sector. He, then managed the Save the Children USA 'National Chid Survival Action Programmes' and later moved to Save the Children Norway. His research interests include 'public health', 'child deafness and communication', disability and development, inclusive education, cultural diversity and 'community-based rehabilitation'.

ORLAITH GALLAGHER

Orlaith has worked on Landmine programmes and with UNICEF to promote mainstreaming of disability activity into all UNICEF programmes. she was the Project officer for the Mine Risk Education (MRE) programme which was a joint venture supported by DfID and UNICEF to strengthen programming as it applies to humanitarian activities.

SALIF GANDEMA

Salif Gandema is a doctor who specialises in physical medicine and physiotherapy. He is also specialised in orthopaedic devices for physically disabled persons and life insurance. He is the focal point of CBR for West Africa. After being head of the National Centre for Orthopaedic devices of Burkina Faso (CNAOB) for about ten years, he is presently assistant to the Head of the clinic of the Polytechnic University of Bobo-Dioulasso (Burkina Faso).

MARTHA GEIGER

Martha recently joined Disabled People South Africa (DPSA) to develop a research portfolio for the organisation. Prior to this, she was teaching and researching in the Division of Communication Sciences and Disorders at the University of Cape Town. She has also worked in Botswana for twelve years where she gained her initial experiences in Community Based Rehabilitation (CBR). Her research interests include culture and disability, community-based interventions for children with severe disabilities and participatory learning and action as a CBR strategy.

TIGABU GEBREMEDHIN

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SALLY HARTLEY

Sally has worked with and for disabled people in many Africans countries over a period of 35 years. She a PhD in public health and is presently Professor of Communication and Health at the University of East Anglia, UK and Executive Director of the CBR Africa Network (CAN). She is also an advisor to the Disability and Rehabilitation Section of the WHO as a contributor to the new WHO CBR guidelines and as one of the editors of the World Report on Disability and Rehabilitation due out in 2009. Her research has focussed on developing effective partnerships with all stakeholders and using community approaches to improve the quality of life of people with communication disabilities in low income countries.

ANNE HERTZBERG

Anne is a Technical Advisor in Disability Department, Ministry of Public Health in Afghanistan since September 2006. Before she had the same responsibility in the Disability Programme of Swedish Committee for Afghanistan, the programme is based on a CBR approach. Until 2004 she worked with different assessment, evaluations and project advice to community based programmes related to disability and health in Southern and Eastern Africa. In 2002 she was secretary for the development of Guidelines for the Inclusion of Disability in Norwegian Development Support for Norad. In 1996-1999 she was technical advisor for Rehabilitation Division, Ministry of Labour and Human Welfare in Eritrea on the development of a National CBR Programme.

MARIA KETT

Maria Kett is the Assistant Director of the Leonard Cheshire Disability and Inclusive Development Centre, University College London. She leads the team in planning, implementing and monitoring research projects in the field of disability and international development. She is also honorary lecturer in 'Conflict, Migration and Human Rights' at the Centre for International Health and Development at UCL. She has a particular interest in disability-

related issues in situations of disasters and conflicts, and is currently Chair of the International Disability and Development Consortium (IDDC) task group on Conflict and Emergencies. Her other main research interests include social exclusion; psychosocial impacts of conflict; effects of displacement, and broader health and development issues. She completed her doctorate in Social Anthropology at the School of Oriental and African Studies, University of London in 2002. Her thesis focused on health and well-being in suburban China.

CHAPAL KHANSNABIS

Chapal graduated in Prosthetics and Orthotics Engineering from the All India Institute of Physical Medicine & Rehabilitation, Mumbai, India He then joined the National Institute for the Orthopaedically Handicapped, Government of India where he eventually became the Head of the Bio Engineering Department. He also founded and NGO, 'Mobility India'. Chapal has worked in Nepal, Bangladesh, Sri Lanka, Mongolia, Vietnam, Guyana and SierraLeone. He is currently a Technical Officer in the Disability and Rehabilitation team in the department of Violence and Injury Prevention and Disability. His responsibilities include the promotion of Community-based rehabilitation (CBR) and assistive devices (especially prosthetics/orthotics and wheelchairs). He uses his 30 years of work experience in government, NGOs and International Organizations to promote rehabilitation services focusing on developing countries.

JUDY MCKENZIE

Judy Mckenzie is a disability and education consultant in East London, South Africa, concerned mainly with disability in rural contexts. She is also active in the local Down Syndrome Association as her youngest child has Down Syndrome. She has taught at Fort Hare University in inclusive education, HIV/ Aids and resilience in children and is currently engaged in her doctoral studies on inclusive education for children with intellectual disabilities at Rhodes University.

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Robert became deaf during his childhood. He is the current Chairperson for youth with disabilities in Uganda under the umbrella organization of the National Union of Disabled Persons of Uganda (NUDIPU); he also volunteers with Uganda National Association of the Deaf (UNAD). Robert was the deputy speaker for Makerere University disabled students association for two years. He represented youth with disabilities of Uganda at the recent 3rd CBR Conference in South Africa where he gave a presentation on the importance of sign language in Community Based Rehabilitation programs.

ALICE BAINGANA NGANWA

Alice is a medical doctor with Masters degree in Mother and Child Health and additional training in Health Services Management, community based rehabilitation, disability research, epidemiology, injury prevention, older persons issues and road safety. She has worked in disability and development for 15 years as a clinician and later as programme manager in the Ministry of Health, Uganda. Dr. Nganwa has contributed to the development of the WHO CBR guidelines and has led several research, training and evaluation teams in disability. She is a founder member of CBR Africa Network. Dr. Nganwa is currently the director of **W**ays for **In**clusive **D**evelopment(WIND).

PETER NGOMWA

Peter is a Head of Vocational Skills Training in Malawi Council for the Handicapped where he has worked for over 22 years, contributing to its mission of implementing government policies by providing rehabilitation programmes and services and promoting public interest (awareness) for the empowerment and integration of persons with disabilities. He has experience of prevention of impairments through better nutrition, proper child development and protection, basic eye and rehabilitation through therapy and referrals to appropriate service providers. He currently works as Chief Centre Manager which involves overseeing vocational skills training institutions in Malawi Council for the Handicapped and is also a member of the national Community Based Rehabilitation Resource Team that trains stakeholders, for the purpose of mainstreaming disability issues.

SYLVIA NTEGYEREIZE.

Sylvia is currently the Assistant Commissioner in the Ministry of Gender Labour and Social Development in the Government of Uganda. She has a wealth of experience in CBR, having worked in CBR since 1975Sylvia played a key role in review of the WHO CBR guidelines and is still actively involved in reviewing CBR guidelines in Uganda.

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Charlotte is a human rights lawyer and works with the World Bank in Washington as a senior operations specialist in the East Asia, Africa and Pacific region and has been on the South African Human Rights Commission since August 1999. Previously she was a Project Officer on Child Protection for UNICEF (United Nations Children's Fund). Charlotte was also Legal Advisor in the South African

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Joan is Coordinator of CBR Africa Network (CAN). She is based at the CAN secretariat at Kyambogo University in Uganda. Joan is particular interested in developing and being part of communication, knowledge and information sharing initiatives, geared towards promoting social inclusion and development in Africa. Previously she worked as an information and documentation officer for Uganda Society for Disabled Children (USDC), an organisation focused on improving access to health, education and social services to children with disabilities in Uganda.

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Orpa is currently the Education adviser for Leonard Cheshire Disability (LCD). Her main responsibility is the management of LCDs Inclusive Education in East and North Africa region but she also provides support to IE projects in other regions. She coordinated a successful model Inclusive Education project – Oriang Cheshire Inclusive Education project in Kenya, currently being up scaled into a Nyanza Inclusive Education programme. She is a holder of MA (Special Education Needs) through EU Commission, and B.Ed

(Special Education). She previously served as an inspector of schools with the Ministry of Education, Kenya, in charge of Special Education in Nyanza Province. Her early career involved teaching visually impaired children in special schools and in mainstream primary schools. She is engaged in action research as a way of improving participation and practice in inclusive education.

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Fiona is a sociologist and Senior Lecturer in the School of Allied Health Professions at the University of East Anglia. She was Project Coordinator for 'The Research Exchange', a charitable organization to link Higher Education with the community in Greater Manchester. For many years she has been a national trustee for the UK Association for Research in the Voluntary and Community Sector which promotes research to support community action. Her career-long research interests centre on community engagement in the health and social support of marginalised groups including people with disabilities, including dementia.

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Andreas Pruisken worked for 6 years in the US in a community outreach program for the underprivileged population in downtown Stamford, Ct. He graduated with a Master of Divinity in 1984 from Yale Divinity School in New Haven, CT. He now works for CBM in the department for Inclusive Development, promoting the rights of persons with disabilities in development programs and establishing alliances with key stakeholders. He previously worked as Regional Representative for Southern Africa based in Botswana and responsible for 120 CBM supported projects on disability and development in 12 countries. Andreas is a member of the Interim Board of the Global Partnership for Disability and Development (GPDD).

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Sarah is currently the manager of a CBR and disability non-government organisation, CREATE, in the KwaZulu Natal province of South Africa. Sarah has worked in the field of CBR training since 1993. She has trained mid-level CBR workers as well as community health workers, therapists and others in disability issues and CBR. Sarah has also conducted research into CBR and she is currently completing her PhD in Community Based Rehabilitation. Sarah has helped to organise a number of workshops and conferences on CBR in South Africa and she is keen to help spread information about CBR, particularly in South Africa. Prior to her involvement in CBR, Sarah trained as a speech therapist and worked in Soweto and other communities around Johannesburg, helping to set up a self-help organisation of people with communication disabilities.

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Mr. Zamo Pate holds a degree in Management and Accounting. Since September 2002, he has been director of PRAHN, a CBR Programme which supports all types of disability in Niger. Mr. Zamo Pate has also been the CBM local representative in Niger since May 2001. He is also a member of the Executive Committee, CAN.

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Rachel is an Associate Professor in the Faculty of Health Sciences at the University of Ottawa, she specializes in Community-Based Rehabilitation, psychosocial care, and issues of meaning and social justice in health care. She has degrees in Health Sciences and Psychology. Her current research for a UN implementing agency the World Rehabilitation Fund, addresses the reintegration of landmine and war victims in countries such as Laos, Cambodia,

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Joe graduated in Prosthetics and Orthotics Engineering from Strathclyde University in Glasgow, UK. He worked in France before joining international organizations in humanitarian work for rehabilitation of war victims and other disabled people in numerous projects mainly in Africa and in Latin America, Pakistan and India. His previous experience includes work as, Technical Advisor of the Omega Initiative program for Africa and Technical Consultant for Medical Care International Development-MCDI. Joe has been involved in changing the ICRC strategy for the standardization and centralization of the production of orthopaedic components to improve the quality of assistive devices. He developed the Patient Service Support (PSS) program in Ethiopia to increase access to physical rehabilitation for disabled person

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CHAPTER 1

The Implementation of Policies in Community Based Rehabilitation (CBR)

Huib Cornielje, Hendrietta Bogopane-Zulu

SUMMARY

CBR is interpreted in a number of different ways across the African continent and these interpretations vary often according to the local practical context. Part of the context relates to the existence or otherwise, of legislation and policies which potentially can affect disabled people and their families, but very often they make no difference at all. Where these polices exist, there are still implementation issues which relate much more to the actual circumstances of people with disabilities and their families. CBR has the potential to play a very constructive role in this implementation process. This chapter reviews key points that may assist in the process and highlights the importance of disabled people becoming part of DPOs and working together with CBR workers to make the lives of disabled people and their families better.

INTRODUCTION

In spite of the clarity of the joint position statement (WHO/ILO/ UNESCO 2004) on Community Based Rehabilitation (CBR), the reality is that CBR is often interpreted differently around the world and means different things to different people. While some people see CBR as service provision only, others see it more as an empowerment strategy. In fact, there is a wide continuum of CBR applications globally. The way CBR is developed and implemented appears to largely depend on eco-social factors (Cornielje et al, 2001). CBR programmes differ from country to country and even within countries, diverse applications can be seen. CBR also differs in organisation, structure, philosophy and scope. The variety of programmes range from those that are basically health service oriented, to those that are empowering, based on human rights issues, socio-politically oriented, and working within a social disability model. Given the local context (e.g. historical, cultural, political, economical geographical) which also includes various stages of national development, this chapter will explore the various types and forms of programmes. It is important to be careful in making judgments about the appropriateness and relevance of programmes. For instance, some political contexts actively promote a socio-political model of rehabilitation and collective (political) rights, which may be at odds with the political environment. It may on the other hand, be difficult to promote inclusive education for blind children in a context in which hardly any trained personnel are available and the only resource available in the field of education of blind children is a special school in the capital of the country.

CBR AS STRATEGY

In spite of the broad range of CBR applications, CBR as a strategy for addressing the needs and demands of people with disabilities in less-developed countries has become the most accepted approach. CBR as it is seen these days has two main perspectives: a rights perspective and a poverty perspective. For a long time, it has been apparent that disabled people should have equal rights, which they should be allowed to enjoy in the same way as the rest of the population. The notion of human rights is clearly demonstrated in the CBR joint position statement of 1994 from various United Nations organisations, but in fact was applied much earlier in reality.

In the Alexandra Township, a slum north of Johannesburg, CBR was regarded as a strategy aimed at addressing the struggle for human rights and more specifically the rights of disabled people. CBR in the political context of South Africa in the late eighties and early nineties was a strategy that was used as a political instrument to ensure that disabled people were getting a stake in the process of political change. In so doing, it helped to meet their needs and demands for equal rights and opportunities. Secondly and most importantly, we know that people with disabilities are often among the poorest people of society and recently, CBR has also focused on this connection and the role that CBR can play in the poverty alleviation process.

CBR, as it developed in the late 1970s and 80s, was largely a response to try and deliver rehabilitation to people with disabilities at the community level. CBR in those days developed from within the medical model and thus, it largely took place in the context of the health sector and was concerned with individual change and coverage. CBR in those early years focused largely on the notion of "Rehabilitation for All", much in line with the WHO strategy of "Health for All" (Helander E, 2007).

Although accusations have been made by some critics that CBR as presented in those years was largely a top down development – some critics even talk about "Geneva - Based Rehabilitation", the reality is that most CBR developments were more bottom-up grassroots initiatives, managed by non-governmental organisations (NGOs), rather than government controlled programmes. A survey among 29 African countries[1] compiled by M. Giannelli and S.

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[1]   Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Central African Republic, Congo Brazzaville, Democratic Republic Congo, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Kenya, Liberia, Madagascar, Malawi, Mauritania, Mozambique, Namibia, Rwanda, Senegal, South Africa, Swaziland, Tanzania, Tchad, Togo, Zambia, Zimbabwe

Deepak (WHO DAR Team, 2003a, p. 15), suggests that there is "no national programme (in these countries) where multi-sectoral CBR activities cover the whole country". CBR is mostly confined to pilot projects in some areas of a country, with foreign funding. Three countries (7%) had already given up on CBR, closing down their attempts at national programmes, while fourteen (48%) of the countries surveyed never started. Botswana was one of the first countries where WHO introduced CBR, with the early WHO training manual being translated in Setswana, the major local language. However, the country has not yet adopted a rehabilitation policy that mentions CBR as a (preferred) strategy and CBR in Botswana is still developed and managed by the NGO sector.

The original CBR initiatives with a focus on coverage and on individual rehabilitation became a caricature for all that was and is CBR. It is however, questionable if this position gives recognition to the numerous efforts of many concerned professionals and CBR staff, to really make a lasting difference in the lives of disabled people. Is the ability to walk; the ability to make use of public transport; and the ability to become employed and generate an income, not the effect of the advocacy and lobby campaigns that disabled people have been working for? The availability of services, the access to public transport and equal opportunities to become employed, are in fact, the outcome of awareness raising campaigns, advocacy and legislation and thus of disability rights.

The more modern and politically correct forms of CBR, based on social model thinking and human rights, tend to be seen as the best, the ideal, or even the only 'true CBR'. Such strategies may be seen as the only way to ensure that disabled people become part of the mainstream. Let us however, be careful and not fool ourselves and others by using the 'rights' jargon while not ensuring the **appropriate** implementation of these rights. We may think that a person with leprosy is helped with an income generating project (a rights based approach), but if people in the community will not buy

food from their shop because this person is still having severe ulcers, this strategy may not be the best way forward. Conversely, the orthopedic appliance given to someone with an amputation (medical rehabilitation) may in fact be a more immediate stepping stone for social integration and participation in the community, than laws and legislation.

CBR is – rightfully in our view- nowadays seen as an empowering strategy. However, in view of the earlier remarks, some concern should be made about pertinent individual human rights as they may create false 'dawns'. People cannot live on rights and legislation; disabled people will not have automatically a better quality of life because of legislation only. It is the implementation of the legislation that matters in the end. A former Dutch politician clearly indicates the limitation of legislation, in the following quote, *"You cannot develop by act of Parliament" (B. de Gaay-Fortman, 1984).* Therefore, we should ensure that those who engage themselves in CBR will need to continually provide the best possible services to disabled people as well. In order to make CBR successful, it should comply with the following criteria:

- Programmes should involve multi-disciplinary teams, or staff adequately trained about all aspects of disability and rehabilitation.

- CBR teams should be able to address most problems that confront them.

- CBR teams should be aware of their own limitations and where appropriate timely referral to specialist levels of care and rehabilitation.

- CBR teams should develop programmes that are based on needs as expressed by the client groups.

- CBR teams should have the right expertise: in most cases it means that sufficient attention should be paid towards the

training of CBR staff in community development as well as technical skills.

- CBR cannot exist in isolation; CBR is in fact, complementary to mainstream services and to more specialist services offered by various rehabilitation professionals.

Only if such a structure is in place whereby professionals, CBR field staff and disabled people work together, will CBR have the opportunity to become an appropriate strategy. This will allow people to enter a network of services, each part having its own areas of expertise. In such a model, disabled people will be enabled to take their full share in society.

CBR AS POLICY

Public policies are developed through a political process, in order to address public issues. Government and its institutions play a vital role in formulating policy, though it is not government alone that constructs policy. In creating public policy, policymakers and planners are faced with two distinct situations. The first situation and the ideal one, is for policymakers to reach a consensus about the needs to be addressed in close consultation with the community, to translate them into policy problems and define the desired future direction. Subsequently, policy alternatives need to be developed and the best options selected, to move towards the desired future state. During implementation of the policies, monitoring progress should allow for the necessary adjustments and of course the outcome and impact of policies should be evaluated too.

Unfortunately, in reality the policy processes seem to be more a matter of "muddling through", without clear goals and guiding principles and often accompanied with 'half- baked' measures, which ultimately and expectedly lead to dissatisfaction with those measures. It is usually the measures that are blamed for failure. While

a growing number of African national states do have legislation on disability (e.g. South Africa, Uganda, Tanzania) and rehabilitation (e.g. Rwanda), only few have adopted a CBR policy as the national rehabilitation policy (such as Namibia and Uganda). Some countries have draft policy on CBR (e.g. Zambia); others have adopted principles of CBR (e.g. the Ministry of Labor and Human Welfare in Eritrea). It may be that the hesitation to accept CBR as a national policy for rehabilitation is based on a lack of evidence that CBR has the desired effect in terms of coverage, effect and impact on the (quality of) lives of disabled people. Without this evidence there is a tendency for the policy makers to assume that CBR has low coverage and high costs per person. There is a complete lack of evidence about the numbers of people who ultimately leave the CBR programme because they are fully integrated into society. Evaluations of CBR programmes frequently mention these shortcomings and come to vague and unsatisfactory conclusions about the quality of services; outcome and impact. This is severely affected by a general lack of records and absence of transparency. In addition, gathering evidence on the effectiveness of CBR with rigour and research credibility, poses considerable challenges to the research community who are challenged by the complexity of evaluating such a multi-faceted intervention with heterogeneous groups, in different cultural settings and with no 'hard' outcome measures yet available.

The low interest in developing CBR policies might be attributable to the complex interaction of many factors, e.g. original CBR principles of working with volunteers and involving communities seems not to have worked in most African communities; professional protectionism combined with antagonism towards CBR from within the disability movement, which in a country such as South Africa has been the underlying cause for failure to accept CBR as a viable strategy (Cornielje and Ferrinho, 1999). However,

other, more macro-developments may underpin the lack of interest and belief in CBR, for meeting the needs of many people in Africa. To name a few: the rise of HIV-AIDS; increasing African urbanisation mostly in slums, with the related decrease of the rural community with its traditional systems of mutual support.

In order to develop acceptable and appropriate policies, policymakers should ideally be guided by the following core principles:

1. Politicians and policy makers should always be **accountable** to the public.

2. Politicians and policy makers do not have the right to pursue their interests without constraints. Their **legitimacy** is obtained from the public whom they should serve.

3. Government decision processes must be open, accessible, and **transparent**, as well as being responsive to public concerns.

4. Individuals and communities have the right to information regarding proposed developments; the right to challenge the need for and the design of projects; and the right to be involved in planning and decision-making processes. They too have **power** and should be allowed to exert their power as well.

In addition, demands from the general public or "bottom up" initiatives, can and should be as influential as "top down" directives. Communities are increasingly educated or at least informed (through various forms of media), and can mobilize themselves to demand and support desired initiatives.

Powerful special interest groups such as Disabled People's Organisations (DPOs) can and do apply – at least in democratic

national states - significant pressure on elected officials and public servants in order to achieve their ends, regardless of the public welfare. Examples of such influence by DPOs can be seen in Uganda and South Africa. However, opportunities for exercising influence are still limited in many parts of the world for disabled people because of discrimination, negative attitudes and stigma.

CBR WITHIN THE CONTEXT OF THE UN CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES (CRPD)

The UN Convention on the Rights of People with Disabilities (CRPD) was not yet ratified during the Johannesburg conference (upon which this chapter is based), but subsequently in April 2008, it was ratified by 20 countries. The UN Convention provides a new instrument for ensuring equal opportunities for disabled people. It may also form a powerful tool to ensure further CBR development. In spite of some opposition towards CBR from Disabled People's movements - who see CBR personnel just as much as 'an enemy' as professionals – the Convention makes room for Community Based Rehabilitation (article 26) where it states, *"Support, participation and inclusion in the community and all aspects of society are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas."* Interestingly, this article implicitly refers to CBR, even taking into consideration the fact that coverage and access to rehabilitation services is often marginal; something which certainly applies to the African continent.

CBR is not an end in itself, but it is an approach or means of ensuring integration and equal rights. An interesting question is whether CBR can be seen as successful, if equal rights for all have been achieved? While most people may agree with this, others would be more hesitant and prefer to critically follow the process towards implementation of those rights. A disability activist from South

Africa expressed some concerns on an e-mail list and asked herself, *"What does the treaty mean to Lawrence Nkumba from N'wamitwa village in the deep rural area of Tzaneen in Limpopo Province? I am mindful of the Advocacy Road Show by the Department of Public Service and Administration which I'm not sure if DPOs have been consulted and/or are involved. We need a stronger civil society to avoid a situation where government is talking to itself. I think we need to start an implementation process so that ordinary people with disabilities can start benefiting from the conducive environment brought by progressive legislation in our country…"* (Magic Nkhwashu, 02-04-2007).

Rights without implementation and enforcement are meaningless and therefore it is time that CBR implements meaningful programmes to those who are in need. The majority of disabled people in Africa are not organised into DPOs and even large numbers of members of DPOs are not benefiting from legislation and programmes set up by DPOs. It is those people in the periphery of the country; those living in slums who probably never did hear of national legislation, let alone the UN convention, but who long for a better quality of life. It is those people who are denied their rights to even the most basic amenities; and it is those people who could be reached with well planned, good quality CBR programmes. It is also those people who do best understand that *"no one in ... society is completely independent, for we live in a state of mutual independence" (*Mike Oliver, 1991), or in the word of the Maasai proverb *'no one head contains all wisdom'.*

Rights may be useful if you can take someone to court. That may be possible for the urban elite living in a conflict-free, open and democratic society, but is hardly imaginable for the poor rural masses and those living under illegal conditions in slums of the cities of Africa. In such a context, the rights of disabled people are best served with CBR programmes that seriously take into consideration the basic principles of CBR as described in the new CBR Guidelines.

TEN GUIDELINES FOR POLICYMAKERS AND CBR PLANNERS

The development of the new WHO/ CBR Guidelines is described in another chapter. It is expected that the new Guidelines will form a practical tool for those who are involved in CBR at a policy, planning and management level. In order to remind us on a more daily basis of the most important guidelines and principles, a memory aid in the form of an acronym is suggested. The acronym, not surprisingly, is formed by all ten letters that form the word DISABILITY. The ten principles read as follows:

- Recognise **D**iversity.

- **I**njustice should be eradicated.

- **S**pecific services where needed but mainstream where possible.

- **A**ssess to what extent the programme is affordable, sustainable, of good quality, appropriate, effective, networking, collaborating and making use of local resources.

- **B**elieve in belonging and ensure that projects are truly inclusive and apply the principle, "*nothing about us without all of us*".

- **I**mplement diversity and pay specific attention to women and children.

- **L**abour is an important stepping stone for inclusion and acceptance.

- **I**nfluence should be ensured and thus become involved in advocacy; be accessible yourself and include disabled people in planning, implementation and evaluation.

- **T**raining which is empowering for individuals and organizations.

- **Y**ou can make a difference in the life of others and yourself.

Disability in this form, provides guidance to possible solutions. Such action can help to combat injustice in society.

In terms of types of CBR programmes needed, a continuum can be recognised with distinct CBR models that can be positioned on the basis of their philosophical starting points and subsequent approaches: at one end of the continuum, the benefits of programmes using the medical model can be recognised and at the same time it can also be seen that action based on the social model can be effective in improving the lives of disabled people and their families (Cornielje et al, 2001). These two 'contrasting' models provide us with insight into a number of characteristics and principles, which in turn help in determining what approach best suits the needs of a particular population. It should be noted that although the social model is viewed by many activists and professionals as the most desirable and optimal model of CBR, the various mixed models have significant value as well. In fact, within the social model, several characteristics of the individual model can serve to bring serious meaning for people with disabilities. A strong element of complementarity within the apparently 'contrasting' models should be recognised and appreciated. As stated earlier, CBR should evolve within the local eco-social context, rather than following a top-down blue-print.

It is notable that few national CBR policies do exist in Africa. Some may argue that national policies and programmes may have a detrimental effect on CBR development, as national progammes are usually organised from top-down. There is some validity in such a position. Yet, as shown in this chapter, policy development is a complex and dynamic process in which various stakeholders have a role to play. Thabo Mbeki – rightfully – has the opinion that a society should be judged on its ability to take care of vulnerable people (including those disabled people who live on the fringes of society). These people can become actively organised into DPOs and work

hand-in-hand with CBR personnel. They can help to ensure that policy makers, planners and government institutions are influenced by them. Together, they can help legislation and subsequent policies to be adopted that allow programmes to develop with a community focus and at their own pace. In an ideal situation with national CBR policy, it is up to government institutions - possibly with assistance of UN or other international agencies - to set guidelines for monitoring and evaluation; to provide resources and build the capacity of institutions, organisations and individuals. In such a mutual agreement they can develop their own contextualised CBR programmes and there should be plenty of room for Africans to determine their own development in a spirit of Ubuntu.

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Role of DPOs in Policy development and implementation of CBR

International policies, legal frameworks and CBR

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SUMMARY

This chapter examines how international policies such as the Millennium Development Goals (MDGs), Poverty Reduction Strategy Papers (PRSP) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) relate to CBR as a strategy for inclusive development. The MDGs adopted at the UN Millennium Summit in 2000 define the goals for international development up to 2015. Poverty Reduction Strategy Papers (PRSP) initiated by the World Bank and the IMF are a major operational strategy for the implementation of the MDGs. The UN Convention on the Rights of Persons with Disabilities has changed the political framework of national and international policies on disability by making a paradigm shift from viewing disability as medical or social welfare matter to a human rights issue. And it covers the full range of human rights of persons with disabilities from civil and political as well social and economical. These policies address poverty and thereby disability as a consequence and cause of poverty.

The political, economical and social environment for comprehensive CBR is on one hand, affected by all three international policies creating opportunities and challenges. On the other hand, CBR offers them a highly appropriate and effective strategy for the implementation of inclusive development.

INCLUSIVE DEVELOPMENT

Inclusive Development is a consistent and comprehensive approach. It pulls together diverse aspects of social and economic development and provides a clear conceptual framework and practical guidance. It builds on stakeholder engagement, wants to strengthen local institutions and is operationally relevant. To engage at micro level and address systemic change is essential. Effective inclusive development recognises that disability is a cross cutting issue and affects all aspects of planning. Involvement in the process requires innovation, flexibility and evidence based practices as well as a multi- sectoral approach.

Tools for inclusive development include the UN Convention, PRSPs, MDGs as well as CBR and inclusive education. Inclusive development takes place when the rights of persons with disabilities are recognised, their voices heard, they participate in decision making and in life in society. Empowerment is a key activity and it requires sharing of knowledge and power. One outcome of inclusive development is poverty alleviation and the improvement of the quality of life of persons with disabilities.   This twin track approach ensures both supporting specific initiatives to enhance the empowerment of persons with disabilities, as well as mainstreaming disability in all strategic areas of development cooperation.

GOAL SETTING: THE MILLENNIUM DEVE-LOPMENT GOALS (MDGS) AND DISABILITY

The MDGs are an ambitious global campaign to reduce absolute poverty by 50% by 2015 and by defining seven other international development goals and implementing these in a concerted and focused world wide effort. The goals are designed to be a tool for measuring specific results. However, the MDGs do not include disability, even though disability is both cause and consequence of poverty. There are approximately 650 million persons with disabilities in the world, or 10 per cent of the global population. An estimated 80 per cent of these persons live in developing countries, many in conditions of poverty. In both developed and developing countries, evidence suggests that persons with disabilities are disproportionately represented among the world's poor and tend to be poorer than their counterparts without disabilities. It is estimated that of the world's poorest people, meaning those who live on less than one dollar a day and who lack access to basic necessities such as food, clean water, clothing and shelter, 1 in 5 is a person with disabilities (Elwan A. 1999) . Given that persons with disabilities represent such a significant proportion of the population, and are more likely to live in poverty than their peers without disabilities, ensuring that they are integrated into all development activities is essential in order to achieve international development goals.

There is a strong bidirectional link between poverty and disability. Firstly, poverty may cause disability through malnutrition, poor health care and dangerous living conditions. Case studies in developing countries show that higher disability rates are associated with higher rates of illiteracy, poor nutritional status, lower immunisation coverage, lower birth weight, higher rates of unemployment and underemployment, and lower occupational mobility (Elwan 1999). Disability can cause poverty by preventing the full participation of persons with disabilities in the economic and social life of their communities, especially if the appropriate supports and accommodations are not available (World Bank, accessed 2008).

 The high numbers of persons with disabilities who are disproportionately represented among the world's most marginalised groups have a profound significance with respect to the achievement of the Millennium Development Goals, which thus far seems to have gone largely unnoticed in the international discourse on the

Goals (UNESCO 2008). On the basis of this evidence, it is essential that disability needs are addressed and included in all of the eight MDGs:

MDG One: Eradicate Extreme Poverty and Hunger

- The prevalence of disability is about 10% of the world population. Due to the close link of poverty and disability, extreme poverty can only be overcome by including persons with disabilities in poverty reduction programmes. Not addressing the barriers that persons with disabilities face in escaping poverty seriously undermines the effectiveness of anti-poverty programmes.

- Disability impacts the entire families' labour force participation and schooling.

MDG Two: Achieve Universal Primary Education

- Of the 115 million children not attending primary school in the developing world, about 40 million are estimated to have disabilities.

- The United Nations Educational, Scientific and Cultural Organisation estimates that 98 per cent of children with disabilities in developing countries do not attend school. (UNESCO, accessed 2008).

MDG Three: Promote Gender Equality and Empower Women

- Women and girls who are poor have the least power of anyone in society. Moreover, violence against women is an important cause of both psychological and physical disabilities, and some disabilities – such as obstetric fistula – are particularly stigmatizing.

MDG Four: Reduce Child Mortality

- Children with disabilities are more at risk of dying, not only because of life threatening medical conditions or lack of access to public services, but because in many cultures they are neglected or left to die. Often this results from intense stigma.

MDG Five: Improve Maternal Health

- This goal directly ties in to the notion of disability prevention. Furthermore, disabled women are more likely to be victims of sexual abuse and have less access to public health information, making them at greater risk of unwanted pregnancies, HIV/AIDS and other STDs.

MDG Six: Combat HIV/AIDS, Malaria and Other Diseases

- In essence, people with AIDS have a disability. As with other disabilities, issues of stigma and reduced functional capacity are central.

- Furthermore, to effectively stamp out any epidemic, the entire population must be reached. Current outreach and education efforts are usually inaccessible, although people with disabilities are expected to have higher rates of infection.

MDG Seven: Guarantee Environ-mentally Sustainable Development

- Environmental risks (e.g. poor sanitation and water quality) and natural disasters can cause numerous types of disability.

- Not incorporating universal design into post-disaster reconstruction creates long term barriers to accessibility, at a time when such accessibility could be produced in the most cost effective manner.

MDG Eight: Develop a Global Part-nership for Development

• A partnership implies inclusion, which means everyone

OPERATIONAL STRATEGY FOR MDGS: POVERTY REDUCTION STRATEGY PAPERS (PRSPS)

The PRSPs are designed to be the country level operational framework for progress towards the MDGs, combining goal setting with programmatic implementation. They were initiated by the World Bank and the IMF in 1999 in response to the debt crisis of predominantly low income countries. The basic concept underlying PRSP is that indebted low income countries develop a plan of action on how to reduce poverty and improve the living situation of their citizens. On the basis of a national poverty reduction plan, countries then qualify for debt relief from the World Bank and the IMF and other donors as well as for grants and loans. The PRSPs have now become a major policy instrument in more than 60 countries, are linked to international strategies and policies and used by international development partners. PRSP can in summary, be described as a country's macro economic, structural and social policies and programmes to both **promote growth** and to **reduce poverty.** A number of different stakeholders are involved in the PRSP: the Governments, civil society the World Bank, IMF and international development partners by providing technical and financial support. The PRSP should be country owned and partnership oriented, involving coordinated participation of development partners. The Government is responsible for the overall coordination of the process and civil society are encouraged to participate as much as possible in a structured consultative process. It provides a mechanism for the poor to participate in the policy process.

The primary objectives for the PRSP documents are to:

• Explain the broad based participatory process in all operational steps leading up to the formulation process of the PRSP,

• Describe the poverty profile of the country,

• Set targets and proposed measures within policy measures.

PRSP recognizes the multi-dimensional nature of poverty and is result oriented by focusing on outcomes that benefit the poor. Greater emphasis is given on monitoring the impact of policy changes.

The process of PRS is structured in three main phases: **formulation, implementation** and **monitoring and evaluation.**

The **formulation process -one year:** As an outcome of the poverty analysis, priorities are identified and are the basis for the formulation of the strategy, which are then discussed with the stakeholders until agreement has been reached (Handicap International and CBM 2006).

The **implementation process** lasts three to five years. The poverty reduction strategy can include three components or clusters (illustrated below with an example from Tanzania):

• *Growth and reduction of income poverty*: covering issues such fiscal, trade, employment, energy, food supply, agriculture, etc.

• *Improvement of quality of life and social wellbeing*: addressing education, health, gender, HIV /AIDS, water supply, social protection.

• *Governance and accountability*: dealing with structure and systems of governance, reduction of corruption, public service, etc.

• The monitoring and evaluation process starts parallel to the

implementation phase and is based on the operational targets defined in the strategy. The Government writes an annual progress report for the World Bank and the IMF.

Inclusion of disability in PRSP as a strategy for inclusive development

PRSP provides a mechanism and opportunity for persons with disabilities to participate in the strategy development through its participatory approach. Studies of the World Bank (Bonnel 2004) have also shown that the involvement of persons with disabilities in PRSP changes a social protection /charity approach without their involvement, to an economic / human rights based one. To promote the inclusion of disability in PRSP can be done in the following three steps:

Formulation phase:

In the initial process of this phase it is important to initiate or join a disability or CBR network or to work closely with an existing PRSP network. As a next step, join the consultative process and become part of the policy forums. Then identify key people in the decision making process and lobby them. In cases where the PRSP has already been formulated CBR programmes or networks should acquire a copy of the PRSP, understand the structure of implementation which is organised in decentralised way, study the action points on disability and identify sectors such as education, health, employment, HIV / AIDS, social protection, policies and law.

Implementation phase:

This focuses on lobbying local district offices for the implementation of the national strategy. It also includes becoming involved in the budget process of formulation, debate and implementation for allocation of disability specific activities. Another important activity in the promotion of disability is to support the implementation of

specific objectives such as enrolment of children with disabilities in school, access to health care and HIV/ AIDS programmes, etc.

Monitoring and evaluation:

During this phase, CBR networks and persons with disabilities can make a valuable contribution to the PRSP process by giving feedback from field experience, making

suggestions on collection of information for monitoring systems, monitoring progress of implementation and reporting to national level.

The potential benefits for involve- ment of persons with disabilities in PRS are:

- Promotion of inclusion of disability in the MDGs as the PRSPs are an operational strategy for MDGs,

- Strengthening of the human rights based approach on disability by becoming involved in the participatory process,

- Achieving sustainable support for disability specific as well as for mainstream programmes by allocating budget support.

THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

There is a need for clear mechanisms for advocating African Governments to ratify the Convention and develop instruments for benchmarking implementation and monitoring adherence to the Convention.

The UN Convention:

The Convention is an International Agreement that articulates the rights of persons with disabilities. It is made up of two documents, the Convention on the rights of persons with disabilities which contains human rights provisions. The other part is the protocol to

the Convention on the rights of persons with disabilities, which is a document that sets up an individual complaints procedure. It is a binding treaty that entered into force for States Parties on May 3, 2008, together with its Optional Protocol authorising individual complaints.. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity. It covers a number of key areas such as health, education, employment, accessibility to environment and information, habilitation and rehabilitation. It has looked at these rights to give them a more specific disability focus, but does not create new rights or entitlements. The Convention outlaws any form of discrimination on the grounds of disability in any area of life and guarantees equal protection and benefit of the law to all persons with disabilities. It seeks to promote and safeguard the rights of persons with disabilities, and to ensure respect for the dignity, non-discrimination, inclusion and participation on an equal basis with all others in society.

Ratification of the Convention by the National Government

After signing the Convention, each country's national government must ratify the Convention in order to become a State Party to the Convention, legally bound to implement the provisions of the Convention in their country. Ratifying the Convention means that the government agrees to make its own national laws in harmony with the Convention. This process can happen relatively quickly in some countries, but sometimes it can take years for a country to ratify the Convention and some never do.

The Convention helps to:

- Assist Governments to identify the different stakeholders that are required to implement the Convention and to identify the roles and responsibilities of different stakeholders at different levels.

- Re-orientates Governments to a new thinking of the right based approach to disability, as opposed to charity.

- Assist Governments to establish structures that will advise whether the existing state laws contravene the convention.

WHAT CAN YOU DO?

Mechanisms which can be used to advocate for Ratification of the Convention include:

Participate as an advocate for disability issues. Ensure that the Convention is ratified and disability issues are reflected in the country's laws, policies and practices. Know the facts about the Convention and disability. Educate others, e.g., government officials and representatives making decisions affecting lives of persons with disabilities. Speak out to the community as it is important to change societal attitudes. Use of the media: use media to disseminate information.

Network - find partners and allies, who have a common interest in supporting disability rights. These can be specialised groups such as Human Rights organisations, women activists, marginalised groups; and give them information about the Convention and the need for ratification. Create coalitions that are inclusive and representative of diverse disabilities. This builds support and legitimacy for your issues.

Lobby - strengthen your relationship with local and national government, because they are the ones who decide whether to ratify or not. Strong relationship with government officials makes advocating for ratification of the Convention more effective. You can write to your government and urge them to ratify the Convention. Discuss the Convention directly with your members of Parliament. Meet with your contacts in various ministries and local Government

Instruments for Benchmarking the Implementation, ideally the benchmarks should be linked to service delivery level and projected targets over the medium and long term. As these are defined by countries, they need to be captured and monitored systematically. One route for establishing benchmarks at the level of outcomes will be to incorporate them in regular surveys conducted by the country's National Bureau of Statistics. For reporting purposes, there is need to develop indicators on the various rights. Civil society, in particular those of persons with disabilities, should be included in the implementation and monitoring exercise. States should have in place structures to implement the Convention such as the department or unit. A focal officer to handle the implementation of the Convention is helpful. Design a coordination mechanism to facilitate related actions in different sectors and at different levels. This could be the National Council for Disability or Equal Opportunities Commission or the national Human Rights Institutions with clear strategies to meet the Convention objectives.

Specific regulations that are in line with the Convention to be developed or reviewed include:

- Policy on Disability

- National Council for Disability Act enacted and operationalised

- Persons with Disability Act

- Equal Opportunities Commission

- Policy implementation guidelines developed and disseminated

- Action Plans for implementing developed National Programmes provide social support and safety nets to persons with disabilities

- Human Rights Commission established

- Mechanisms to follow up human rights abuse developed and implemented

- Projects on human rights advocacy established for purposes of influencing policy information and enacting laws

- Periodic questionnaire on the implementation of the Convention to both government and civil society organiations developed

- Sign language formalised as a medium of communication

- Braille and tactile formalised as a medium of communication

- National Bureau of Statistics integrates disaggregated data on disability in the National Surveys

- Centrally controlled management information system developed

- Media messages packaged and disseminated

- Budget for implementation developed and provided

- Institutional framework put in place

- Must agree on targets on each article to come up with clear, realistic indicators

HOW CAN THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES HELP US TO IMPROVE THE LOCAL HEALTH AND SOCIAL SERVICES ?

1. Services for all in local health and social services

In Article 2, the Convention gives some definitions. Universal design refers to designs that ensure that ALL people can use ALL services. Several articles in the convention specify that services should promote access for all people. The fields concerned are: education

(Art 24), health and reproductive health (Art 25), social protection and poverty reduction programmes Art 28).

What can we do?

The Convention requires us to take measures to give equal access to services for all. For instance, physical and communication accessibility are good first steps. In Togo, a national survey in rehabilitation centres done in 2005, showed us that several physical rehabilitation units were not accessible for persons with physical disabilities, especially in the rainy season. After this survey, some DPOs have claimed their right to access and some rehabilitation had been done by Handicap International. It is important to say that it was the DPOs who instigated the change.

To illustrate what can be done to prevent discrimination based on disability, the goal of a project in Mali was to allow all mothers to give birth within the community services. Through training and awareness-raising, mothers living with disabilities were able to convince services that they have to accept them.

2. Community based services

Community based services is the second essential point in the Convention about services. Article 19 describes the right to live independently in the community. Firstly it points out that community services for the general population should be available to persons with disabilities. Secondly it emphasises that community services should be responsive to the needs of persons with disabilities. The aim for persons with disabilities is to have the opportunity to live within their local community.

Article 26 specifies that appropriate health and social services have to be available at the community level, including in rural areas. Many CBR projects in Africa are in rural areas, for example in Sierra Leone, Mali and Togo.

What can we do?

Mainstreaming and advocacy can be used to adapt general services to meet the needs of disabled people and their families. These needs can be identified through

proper evaluation of the needs of the community and persons with disabilities.

3. Participation

Participation of persons with disabilities and their representative organisations is included in Articles 3 and 21. Participation is the main process for changing the situation and improving the services. With participation, we are talking about 3 levels: firstly, individual level as a user; secondly, service level as group of users; thirdly, system and policies level.

DPOs operate at all levels but we have a lot to do to improve the freedom of expression and the access to information in many services in West Africa.

What can we do?

We have to facilitate the DPO involvement in services at the three levels. It is a big challenge to improve the quality of services in the name of human rights. We also have to encourage the awareness-raising for the village population with specific methods such as GRAAP in West Africa.

4. Professionals and staff working with persons with disabilities and services

The last point about services and the UN Convention, points out the role of professionals and staff to be accountable for the rights of persons with disabilities. Four articles refer to the professionals. They highlight training: training on the right to better services guaranteed by those rights, training on accessibilities issues, training of health professionals to promote the initial and on-going training

for persons working in rehabilitation services. Article 25 requires professionals to provide care of the same quality to persons with disabilities as to others, with reference to choice, affordable cost and proximity.

What can we do?

We need to facilitate the DPO involvement in services provision and to create links between professionals and DPOs with proper common activities like outreach activities, survey, steering committees, etc. For instance, In Togo, for two years, DPOs have been involved in the process of 'consultations itinérantes', like outreach activities done by the rehabilitation centres. DPOs are responsible for doing the first information, the awareness-raising. Then, they accompany the persons with disabilities during all the process until the payment. In 2008, they will begin the follow-up. It is a real revolution and it needs empowerment and a lot of work to create links between professionals and DPOs. Professionals have to accept the voice of DPOs. It's easy to say, it isn't easy to do.

How to use the UN Convention?

The UN convention could be used to:

• Advocate for access to quality services

• Develop more projects to support ordinary services to become inclusive to people with disabilities

• Reinforce support services (technical aids / rehabilitation / personal assistance)

• Support specialised services (specialised education, specialised employment, community residential services); support their development for people with complex dependency needs

• Promote the link with ordinary services, and be subject to

the general system (same quality criteria and evaluation as ordinary services)

In order to increase our understanding about service delivery systems of the country, we need to:

• Be able to develop service projects in relation with an analysis of state and non state actors, law, regulation, funding mechanisms, policy development and reform process

• Develop quality assessment tools together with state and non state service providers at country level

• Link service activities in the national context to find solutions for sustainability

To promote empowerment (capacity for participation) of users and organisations of people with disabilities we need to:

• Make resources available to support this participation

• Increase activities to support the participation with information / meeting between users / peer counselling etc.

• Develop a methodology that enables users to participate in programming and evaluation of services

• Develop "mediation" between service providers and users

To increase the involvement of persons with disabilities in training and education of health, social, rehabilitation professionals:

• Persons with disabilities can train professionals about their needs and the way to be involved in decision making treatment

• Professionals are trained about the principles and contents of disability models and rights

To support national advocacy activities for access to services (DPOs / NGO service providers):

• Increase awareness about inclusive approach (ordinary /

support / specialised service)

- Be involved in general system reform process in the field of education, e.g., to advocate for inclusive education

- Advocacy for social protection extended to all persons with disabilities for access to services (affordable cost)

- Anti discrimination law

CBR AND INTERNATIONAL POLICIES

> **CBR is a strategy towards inclusive development. The Convention has created a new political reality and defines a comprehensive framework for inclusive development. In this way it underpins and supports the CBR strategy.**

The Convention marks a paradigm shift from disability as a social welfare matter to a human rights issue, which addresses societal barriers and prejudices as disabling factors and seeks to address them. In this way it underpins the future framework of CBR. Furthermore, the CRPD demands the full inclusion of persons with disabilities in development programmes.

As a human rights instrument, the Convention aims at

- ❖ strengthening persons with disabilities to participate in society on an equal basis,

- ❖ covering civil and political as well as social and economic rights,

- ❖ Governments, which ratify are required to ensure that people with disabilities are able to enjoy their rights and recognise that they are right holders,

- ❖ Obligates society to create a 'society for all' free of barriers and without prejudice

As an instrument and benchmark for inclusive development, the Convention

- ❖ Addresses disability as a consequence and cause of poverty

- ❖ Promotes the inclusion of persons with disabilities in MDGs and PRSPs

- ❖ Ensuring that people with disabilities have equal access to social opportunities, education, health, employment

To develop international cooperation and partnerships, the Convention

- ❖ Article 32 states that implementation is the joint responsibility of the countries and the development actors

- ❖ It highlights the importance of including people with disabilities in development

It can be expected that the implementation of the Convention will create a global political dynamic to mobilise financial and technical resources for strengthening the capacities of DPOs to participate in the implementation of the Convention. By recognising the intersect between disability and poverty, the CRPD seeks to ensure that disability as an issue is included in PRSPs and MDGs.

This will assist CBR to achieve these goals. The new WHO definition of comprehensive CBR and its soon to be published CBR guidelines with its matrix of five pillars - Education, Health, Livelihood, Social and Empowerment - correspond to and reflect the comprehensive framework of the Convention and are a powerful tool for the implementation of its different facets.

From an **economical side,** the inclusion of disability in PRSPs can be facilitated through the **empowerment of persons with disabilities** to participate in political decision making process. The PRSP offers CBR programmes the possibility to be included in national budgets and can thereby provide long term sustainability

and strengthen livelihood programmes of persons with disabilities.

From the viewpoint of **development**, the MDGs provide benchmarks for international development, which can only be fulfilled by including persons with disabilities in all of the eight goals. CBR programmes can be an important catalyst to ensuring that this happens at a local level. In addition, CBR me can well be engaged in the monitoring of progress made on the ground, for example in the key areas of **education and health** in the process of the implementation of the UN Convention.

CBR programmes working in partnership with disabled and non-disabled persons are able to create alliances of major stakeholders required to powerfully and effectively promote **equal human rights of persons with disabilities**.

CBR is an appropriate strategy for achieving this.

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Chapter 4.

CBR: Building partnerships before programmes

Rachel Thibeault, Tigabu Gebremedhin, Orlaith Gallaher, Michèle Hébert.

"At Polus, we don't do programmes. We cultivate relationships."
Michael Lundquist, Executive Director Polus Centre for Social and Economic Development

SUMMARY

This chapter explores why partnerships have emerged as an essential component of CBR and why CBR is not about building programmes, but about partnering for the long term and cultivating relationships. It examines the difference that good partnerships can make to the relevance of subsequent CBR initiatives and to their sustainability. The chapter also gives practical guidance on how to nurture the partnership approach and gives examples from Sierra Leone and Zambia.

INTRODUCTION: WHY A PARTNERSHIP?

CBR is in essence a searching process: it calls upon all present to contribute their knowledge and expertise towards a common goal that has been locally and collectively defined. Since no single individual is identical to another, it relies on trial and error experimentation. Since no single individual can tackle alone the structural violence suffered by people with disabilities, it relies on

equalitarian, diverse partnerships. Tapping the power of participation and partnerships has clearly emerged over time as a *sine qua non* condition of CBR's success (GLADNET, 2002; Helander, 1992; Werner, 1998; Rifkin and Kangere, 2002; Hartley, Nganwa and Kisanji, 2002; Mirembe and Hartley, 2002). Nevertheless, a major challenge within the CBR world is how to establish sound, efficient partnerships. This chapter will describe and illustrate some constructive partnership processes. It will explore some of the main obstacles encountered and offer some solutions arising from real-life partnerships.

BWAFWANO COMMUNITY CLINIC, ZAMBIA

Despite the stifling heat, Hilda vehemently expresses her opinion

"Health? What is health? Health is not only TB tablets and ARVs (antiretroviral medication)! I know that's what's being said, what we read in the papers. But we know health is not just a pill. I want more than a pill! My family needs more than a pill!"

The meeting was called to allow local people with disabilities also living with tuberculosis (which correlates highly with HIV-AIDS, but is socially acceptable) to identify their key needs and start building services to answer them.

Together with the consultation process, a meal is being offered and well over 100 people have come to the event. The granting agency could not quite see the point of the exercise - all the expert reports, internationally and nationally, were unanimous - what people with disabilities living with HIV and TB want is drugs. The agency knows: they've done studies, lots of them. End of story.

But Polus, an American NGO devoted to working with and for people with disabilities, never proceeds without extensive local community consultation. Issues need to be verified in the field and each community's wishes always constitute the ultimate marching orders.

Led by trained local members of associations of people with disabilities, and using a technique inspired of Model Coherency, Social Role Valorisation and nominal group techniques, the group reflects on what matters most and sets its priorities. The participants first discuss in small teams and then share their conclusions with the larger group.

There is tension in the air: the plenary session is about to begin and the final ranking will be debated by the whole assembly. The first rapporteur walks to the microphone, leans his Canadian crutches against the wall and presents his team's conclusions.

"What we need first is food security: pills don't work on an empty stomach. TB tablets and ARVs are useless unless we get food." People nod in agreement.

The second request stirs some deep emotion in the room.

"Second, we want education for our children. We all know we're living on borrowed time. We want to see our children educated, so they can survive when we're no longer there. If they don't get an education, they will fall prey to hunger, violence and prostitution. We have to protect them now."

He continues:

"To pay for food and education, we need jobs. Foreign agencies are too fickle; we need something reliable, stable. We need micro-credit, training, a small plot of land, anything that can lead to a regular income. Preferably micro-credit because finding a job is much tougher for a person with a disability. "

The statement is met with applause.

"We need transportation. Affordable and accessible transportation. Some members in our team are from Ngwerere (a rural community); they can't even get to a clinic for their drugs, never mind being able to get to a job."

He pauses.

"And finally, once we get this, all this, then we can start talking about pills."

Very little debate ensues: all teams see the same needs, in the same order.

Fifth. The request for drugs comes fifth, despite all the expert reports to the contrary. How could that happen? Could it be that people were never truly consulted? Or that they were asked only if they wanted drugs or not, not what truly mattered to them?

This situation reflects what Easterly (2006) describes as the "Planner's fallacy":

Planners determine what to supply;

Searchers find out what is in demand.

Planners apply global blueprints;

Searchers adapt to local conditions.

Planners at the top lack knowledge of the bottom;

Searchers find out what the reality is at the bottom.

Planners believe outsiders know enough to impose solutions;

Searchers believe only insiders have enough knowledge to find solutions and that most solutions must be homegrown.
(Easterly, 2006, p. 6)

Farmer (2004) argues that current policies, of the Planner type, reinforce the longstanding intrinsic structural violence of our societies, a violence that is chiefly directed against the most vulnerable. Participation is not only denied; it does not even exist as a potentiality.

> **At the heart of all CBR partnerships are people with disabilities**

OVERCOMING OBSTACLES TO SUCCESSFUL PARTNERSHIPS

Data gathered from previous experience in CBR projects in South East Asia, the Canadian High Arctic, Central America, the Middle East and Africa (Thibeault, unpublished) point to frequent pitfalls in the establishment of successful partnerships . These pitfalls could be summarised as follows.

> **Pitfalls:**
> 1. Unrealistic goals and lack of focus
> 2. Lack of ownership and insufficient local representation
> 3. Inadequate fit with community needs
> 4. Redundancy
> 5. Group think
> 6. Inadequate fit with national policies
> 7. Inadequate policies

According to Easterly, a good partnership usually does not start with a big dream or some unachievable ideal; instead, it must be specific, rooted in healthy pragmatism and allow for modest initial gains (Easterly, 2006). In the field of CBR, Mirembe and Hartley (2002) echo the same idea:

> *Participation is not something which can be considered present or absent, but something that has small beginnings, for example, the partnership between parents and their children, between two people with disabilities, between two professionals. It is important to nurture these relationships, tobuild on them and to value their importance, so that they can grow in frequency and strength and eventually form a corner-stone of all initiatives.* (p.200)

Founding CBR initiatives first and foremost on relationships helps prevent pitfalls number 1, 2 and 3.I t provides an open platform to discussing the relevance and scale of the objectives that will be pursued. By embedding the CBR programme within the social fabric, local representation comes more readily, ownership is enhanced and participation stimulated. Without denying the functional nature of the endeavor and its well-defined intent, this inherently relational foundation of CBR brings with it renewed energy and commitment. Seeing CBR as a network of relationships also ensures that fit between goals and needs will be routinely evaluated - formally and informally – as the programme progresses. Observations, questions and readjustments emerge naturally in a far more organic manner.

When planning CBR programmes, adopting a thorough and truly community-centred approach for the initial consultation process can help set the tone, strengthen the notion of partnership and foster ownership from the onset. Such a consultation approach has been devised at the University of Ottawa and named the Elzéard method. The name Elzéard has been derived from Jean Giono's "The man who planted trees". The book relates the life of Elzéard Bouffier, a man who spent over 50 years re-growing forests in areas devastated by war and industrialization. Without any formal education, but acutely aware of the intimate relationships connecting all of life, Bouffier managed with minimal means to recreate on his own ecosystems. These have allowed the next generations to thrive. His work has been immortalised in a book and in an Oscar-winning animated feature film bearing the same title.

CONSULTATION STEPS

The Elzéard method consists of a series of steps meant to gradually flesh out the web of relationships encompassing a CBR programme. The first step is to train local leaders, members of the community of people with disabilities, in consultation techniques such as the

nominal group. It is they, and not outsiders, who then carry the consultation process throughout. At first, they consult with their own immediate group, defining intent, goals and strategies. *Their initial focus is on creating a safe space for communication*. In Zambia, people with disabilities have commented on how crucial this element is. Being less familiar with public forums but frequently exposed to ostracism, they expressed a deep need for a context where they felt they would heard and respected. Once a climate of trust is established, the greater group is broken into small teams, as described in the opening vignette, and key questions are asked like: What is most important to us? What do we want to achieve? How? After the core group has defined and expressed its wishes, the leaders move on to consulting with local NGOs. The same questions are asked, rephrased, for example, as "what do you think is most important to people with disabilities?" Local NGOs contribute their answers and the process continues with international NGOs, government agencies, informal/traditional healers, leaders and elders. All meet as separate groups to prevent any potential intimidation. Once all those external data have been collected, the group leaders come back to their core group and ask if the new information changes in any way their initial perspective and ranking. Another nominal then takes place and the group finalises its choice of objectives and strategies. Again, as illustrated in the vignette, the core groups' priorities are often at odds with official positions.

This exercise is one among many that aim to minimise the risk of redundancy and "group think". Coined by Janis in 1972 (Janis, 1972), the term *group think* refers to the danger of cultivating an erroneous, skewed perspective on reality, especially when all members of a group share the same background. They then look at the world through a single lens, a narrow, insular view that leads to faulty decisions. CBR programmes are often vulnerable to 'group think' because of their homogeneity, if not in membership at least in purpose.

After completing the Elzéard process, to help the programmes find their place within their community and to limit further the likelihood of redundancy and group think, another larger consultation must occur. Before implementing any CBR programme, it is suggested to hold a general meeting of all local and international NGOs, informal/traditional leaders and government agencies working on a given issue (e.g. employment for people with disabilities). The exercise is meant to create a conceptual map of existing services, identify gaps and redundancies, and potentiate current resources.

Consultation steps:

A general meeting with about 100 disabled people.

Generate priorities in smaller groups

Groups agree on priorities

Consultation with local NGOs

Consultation with International NGOs

Consultation with Government agencies

Report back to original CBR group.

Modify and finalise priorities

Such steps were taken in Sierra Leone regarding CBR programmes for the war victims. In 1999, the World Rehabilitation Fund (WRF) had agreed to support a community consultation process in order to determine where its prospective CBR programme for people who had been amputated should be established (Thibeault, 2002). The meeting, arranged by SLANGO (the Sierra Leone Association of NGOs), put in contact stakeholders from all levels of government and civil society. The conclusions were astonishing. Duplication of services for the people who had been amputated was ubiquitous and chaotic. Several agencies provided help to the very same target groups, worked in the same areas and had head offices next to each other without having ever realised that there were other players in the field. Two agencies were immediate neighbours, but had never communicated prior to the general meeting. To their surprise, they discovered they had identical mandates and could share resources. Unknowingly, they had been competing all along for grants and goods. Spontaneously, some partnerships then started emerging from the encounter, devoting their efforts to both intervention and lobbying, and doing so in a much more rational fashion.

The consultation also brought to light forgotten populations. As it turned out, given the context, the people who had survived traumatic amputations were relatively well serviced, but two subgroups were found in dire need and without any assistance: the female ex-combatants and the child soldiers. After yet more consultation with the National Committee for Reconstruction, Reconciliation and Reintegration (NCRRR) and the vulnerable groups themselves, it became evident that the female ex-combatants and bush wives (the euphemism applied to girls enslaved by rebel troops) were the most ostracised and neglected of all. WRF thus shifted its initial focus to explore CBR possibilities with them. As a result, the CBR programmes born out of the consultation under WRF's auspices benefited early on from clear connections and supportive relationships in their immediate region. This offered the programmes a sense of belonging, purpose and recognition that could have otherwise taken years to develop.

THE WIDER PICTURE

But finding your place within your community also entails finding your place within the greater national picture and asking yourselves the question: Where do we fit in terms of policies and development priorities? The web of CBR relationships and partnerships extends beyond the programme's surroundings and some commonality and

congruence must be present with regards to national and transnational orientations. Fitting within national policies, rather than fighting against them, often makes or breaks programmes. In the most extreme cases, as was seen in Ghana with the Bill Gates Foundation and PEPFAR (the President's Emergency Plan for AIDS Relief – the massive American world-wide initiative for HIV/AIDS), the absence of collaboration and common vision led to the loss of 85% of physicians, mostly to foreign NGOs. Despite the colossal influx of money, the creation of new programmes divorced from national policies and infrastructures translated not into better health indicators, but in the erosion of the public health care system (Garrett, 2007). Today, a $270 million plan is being implemented to bring back about half of the lost health care workers. CBR programmes never receive financial support of such magnitude and they carry a much lesser impact but, still, they should conceive their inception and development from an ecological standpoint, looking at the sustainable relationships they must maintain with the system as a whole.

PARTNERING FOR LONG TERM SUSTAINABILITY

No statement on CBR as a web of partnerships would be complete without mention of 4 components essential for long term sustainability. The first is the recognition of power differentials within the partnership. A strong desire for equality often brings the partners to a place where differences are not supposed to be acknowledged. People might feel awkward with differences in status and will tend to ignore them. Yet this represents a loss for all parties. Educated, influential parents of children with disabilities usually do carry more weight within society than less privileged or uneducated ones. In a CBR context, by not acknowledging their formal and informal power, they in fact deprive the rest of the

group from important leverage. The key question is not: "How do we make it so that every member has the same influence outside our group? This being by nature an impossibility, one should rather ask: "How can each member put his/her power in the service of the group?" Squarely acknowledging power differentials allows the group to decide just as squarely how to tap that precious potential, as long as equality remains the internal norm.

The second point relates to technical aspects. Partnerships can only be maintained if partners can remain in regular contact. In the Majority world, this often represents unbearable costs and cheap communication must be afforded for all participants to play their role. Some alternatives already exist: cell phones now bridge some of the gap, but are still out of reach for a sizeable portion of the population. Another option is the collective USB key and the Internet café cards. The onus for maintenance and upgrades is on the café, freeing scarce CBR resources for other uses. In Zambia and Nicaragua, this strategy has allowed North-South partners and South-South partners to pursue partnerships that would have been unworkable because of distance. Among the technical aspects, we also find the issue of ongoing training. In Sierra Leone, Zambia and Nicaragua, the people with disabilities surveyed within CBR programmes identified 5 priority areas for training: attitude change and empowerment, human rights, "Training for transformation", microfinance (and skills for writing up grant applications), and principles of sound governance.

The third point has to do with a broadening of horizons: no CBR programme should overlook the fact that the environment is a constant primary partner. CBR programmes promoting activities detrimental to the environment contradict their very own philosophy. CBR is about sustainability and there is no sustainability without environmental stewardship. The selection of income-generating activities within CBR programmes should always take into account

environmental impact and favor the gentlest foot print. In Sierra Leone, a group of young bush wives with disabilities had to decide between fish drying or fish smoking as their income-generating project. European granting agencies would have provided start-up funds for smoked fish, a delicacy in the Minority world. But in the post- war context of Sierra Leone, with major deforestation and lack of access to any fuel, only dried or salted fish made sense. For over 6 months, the young bush wives held their ground with the foreign bureaucrats and eventually obtained funding for a micro business that is both successful and environmentally relevant.

Finally, the last point has to do with attitude. For the past 5 years, all CBR training offered at the University of Ottawa has relied heavily on the writings of Rachel Naomi Remen (Remen, 1994; 2000). An American ex-pediatrician who quit her traditional practice to accompany people through the last stages of terminal illness, Remen has also founded a centre in the San Francisco area to train medical personnel in new ways of interacting. Moving away from the medical model, she has designed workshops and techniques that shift the relationship from a base of hierarchical power to one of cooperation and partnership. The emphasis is on listening, meaning and empathy. Learning to welcome and appreciate differences and to grasp the complementarities that feed partnerships are central features of her teaching. Students who complete this training seem to capture much more readily the spirit and intent of CBR. When dealing with real-life CBR programmes, they understand that cultures different from their own are not broken and need not be fixed. They learn to become attentive partners, open to the relational richness of their chosen work. And as they walk into these new partnerships, they simply want "to touch the lives that touch theirs in a way that makes a difference" (Remen, 2000, p.274).

EXAMPLES OF PARTERSHIPS FROM ETHIOPIA

In Ethiopia the CBR services feel that neither comprehensive rehabilitation nor holistic and inclusive community development can be successful without the involvement of stakeholders. This involvement needs to be based on partnership principles, which as we have seen are: commitment to shared vision and objectives, diversity and complementarity, transparency, proactive communication, respect and trust, participation, flexibility and willingness to compromise.

Three examples of partnerships from Ethiopia are described here, each very different, but each an essential part of the CBR partnership process.

Partnership between CBR workers and traditional practitioners

In Ethiopia and possibly in the context of most African countries, traditional practices play a significant role for individuals or families who are victims of indiscernible health and social problems.

In a suburb of Addis Ababa (capital city of Ethiopia), a CBR project was conducting a door-to-door disability and socioeconomic survey to expand its services. The surveyor detected an emaciated child with burning fever lying in bed surrounded by crying family members. The surveyor told the mother to carry the child and go together to the nearby health centre. The mother bluntly said '*No.*' The surveyor pleaded with the mother saying, *"if the child is not treated now, he may die or become disabled"*. To the surprise of the surveyor, the mother whispered *"I know but can't do it"*. The surveyor offered to carry the child on his back to the nearby health centre which was about 600 meters far from the house of the suffering child and family. She shouted *"No"*. However it seemed that the rest of the family had been getting health services at this health centre, all of them except

this male child of 3 years. The child often fell ill but was never taken to the health centre because his mother was strictly instructed by the father not to take him for vaccination or any other medical treatment. The mother obeyed but has to watch her own child suffer and do nothing about it except shed tears of sorrow and helplessness. The CBR Supervisor got the information and discussed the risk and the solution with the family. Lastly, the children and the mother said *"we have a father; he will spell his curse on all of us if we don't honour his instructions"* This is a social service too! He speaks to their intellect and has a magic power over the community members.

As a result the CBR manager together with the supervisor approached the father *('witchdoctor who has a magic power to command the community members' beliefs and behaviours')*. They entered into discussions and a partnership developed. Finally, the child was referred to a pediatric hospital and saved – all were satisfied and happy, and the partnership continued to prevent similar happenings.

The CBR staff learned a lesson about the hidden and forceful traditional service. The lesson learnt helped the CBR management to give due attention and design a mode of partnership with different interest groups and individuals.

Partnerships between CBR workers and DPOs

For about half a decade, there was no consensus between CBR workers and leaders of DPOs, on the principles and practices of CBR strategy in Ethiopia. However, dialogue was continuing in a gentlemanly like way and implementation and expansion of CBR services were taking place at the same time. For DPO leaders, the concern was at a conceptual level related to *'watering down of rehabilitation processes'* particularly at the level of training CBR workers and also the home-based rehabilitation interventions. To them, the engagement of the mid-and low level CBR workers, as well as the family members in any type of rehabilitation process, appeared not to be feasible or acceptable. Secondly, the view of

some of the professional leaders was only to safeguard and promote the Institution Based Rehabilitation approach. On the other side, the CBR workers were excited to demonstrate and go for the CBR strategy implementation without considering the complementary nature of both approaches. Thirdly, there was a strong feeling held by the CBR workers that the CBR projects work only with children and mothers of CwDs who are not members of the DPOs, and asked *'why do we have to need each other unless one wants to interfere.'* During those days, both parties (CBR Workers, DPO Leaders) seem to have been satisfied with the rehabilitation strategies that they agreed seem to serve their own purpose well. Both could not see the need for having a menu of alternative strategies. However, with the low key howl of protest on the new rehabilitation strategy (CBR), there was a prevailing wisdom of tolerance from both sides. Today in Ethiopia, the focus on competition between the two approaches is gradually being replaced by partnership for maximum achievement in empowering PwDs. The common goal is to enable community members to attain improved quality of life. The CBR projects are moving towards supporting and guiding individual PwDs in CBR catchment areas to organise in a form of Grassroots Cross-Disability Self-Help Groups (GCDSHG) for solving immediate and village level life challenges. These groups are models and a powerhouse for creating full social inclusion, poverty reduction, effecting comprehensive rehabilitation intervention, and enforcing human rights. These groups are the arms and future members, of the existing national associations of persons with disabilities. As the goals for the GCDSHGs are almost similar with that of CBR projects, they can only be met through strong partnership between the two and networking among the stakeholders.

A policy of partnership by UNICEF in Ethiopia

As part of the United Nations reforms (1997) the UN set upon a path to increase effectiveness and efficiency through a united

approach. The Common Country Assessment (CCA) and the United Nations Development Assistance Framework (UNDAF) guidelines were issued in 1999.

These guidelines were to assist the UN in each country to work as a united front with Governments to assess and analyse national development situations, taking into account national priorities, the Millennium Development Goals, and conventions (UNOHRLLS, 2002/3). The UNDAF is the operational response to the Common Country Assessment which quotes that it is a *"collective coherent and integrated United Nations system response to national priorities and needs within the framework of the Millennium Development Goals and other commitments"* (UN OHRLLS[2] 2002/3). These assessments and plans are now in place in Ethiopia. The UN and some civil society groups partnered with the Government in the development of the PASDEP document.

The United Nations Convention on Rights of People with Disabilities (UN 2006) should be one step towards making the rights of PWD realised, however this will only happen if the disability community, Government, development NGOs, businesses and the United Nations develop key partnerships and advocate and lobby to have disability as part of all Government and United Nations strategies.

It is one thing to have the convention ratified by a country, however it is another thing to implement it. Only a united front by all will achieve this.

UNICEF is aware that In Ethiopia our organisation has lagged behind in disability issues, however one hopes that UNICEF will partly make up for this in the next five years. Starting as a new

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[2]   United Nations Office of the High Representative of the Least Developed Countries, landlocked Developing Countries and Small Island Developing States)

partner in the disability field gives advantages and disadvantages to UNICEF. Once advantage for UNICEF is that the organisation has had the unique opportunity to look at the disability sector from all angles in an objective manner, which has helped formalise an innovative and yet challenging five year plan.

UNICEF recognised early on that although much work has been achieved by DPOs, NGOs and the Government in Ethiopia on disability there are still a lot of areas that are untouched and in serious need for attention. With this in mind, UNICEF has tried to focus on areas such as coordination, communication, policy, and mainstreaming. One key aspect of the UNICEF Ethiopia disability plan is to have disability as part of the CCA, UNDAF and PASDEP by 2011. UNICEF realised from the start of the programme that this would only happen if we built partnerships with Government, other UN agencies, DPOs and development organizations and agencies.

The second priority for UNICEF is to develop partnerships within the UN itself. Last year UNICEF called a meeting with all UN agencies working in Ethiopia that were interested or working in the field of disability. From this initial meeting a working group was established and chaired by UNICEF, with UNESCO, ILO, WHO, UNHCR, OHCHR and UNFPA as primary participants.

This partnership helps pool activities and ideas as well as reducing duplication of work. The UN Disability working group is working as a united front to lobby the UN country team and to provide assistance for advocacy events such as 3rd December every year. The UN working group will lobby to ensure that disability is a significant part of the next CCA and UNDAF. In developing these associations it is important to be clear what we actually mean by partnership, Walsh (2006) states that for partnership to work all parties involved must build trust, communicate freely, establish

shared goals, focusing on achievable results and delivering a return on investment.

In practical terms partnering with other sections in UNICEF is not easy, however if we manage to achieve some aspects of active mainstreaming then the difference to people living with disability will be phenomenal.

Presently, we are working with two sections - education and water and sanitation. In education we have managed to connect the special needs education officer in the Ministry of Education (MOE) with the Community Based Rehabilitation network manager and UNICEF. In an education mapping exercise that UNICEF is undertaking, some questions have been added by the MOE related to disability. The results of this mapping should help us understand the issues of children with disabilities and help towards building child friendly schools (CFS) that are inclusive for all.

This CFS model which UNICEF Ethiopia is in the process of piloting in fifty schools was also shared with disability organisations for their feedback and comment.

To ensure the practical aspects of the CFS are implemented for disability, the protection section and Mobility Without Barriers Foundation (MWBF) are in continuous dialogue with education. Although we will have mobility cycles to offer children who have a physical impairment we also want to make sure the schools are truly inclusive.

In UNICEF's Water and Sanitation Hygiene section (WASH), many colleagues who had worked in WASH for years admitted that they had never thought of people with disabilities.

This is shocking and yet very honest. WASH section have now taken the initiative further and discussed many key points with regional authorities. WASH is working with Water Aid, who have made steps to include disability into their programme. The next

steps are to ensure that all contractors hired by regional and district administrations understand and build latrines as well as water points that will be accessible to all.

In the coming months UNICEF's protection section is commissioning a study to look at internal UNICEF programmes with the aim of mainstreaming disability. This will be conducted for parallel government ministries using the Strengths, Weakness and Opportunities and Threats (SWOT) method. The study will also look at DPO capacity in Ethiopia from all angles; the DPOs, partners and donors will be interviewed to get an overall balance of how best DPOs can be assisted to improve their output.

To deal with the lack of communication within Ethiopia, UNICEF has teamed up with the Ethiopian Centre for Disability Development (ECDD). The aim is develop and launch a disability website which will show all the services that exist in Ethiopia as well as research and linkages to other international organisations etc. This website will also be available on CD ROM which will be available to the CBR network, NGOs, DPOs and Government.

If we do not stand together to fight for the rights of people with disability then people with disabilities will always be marginalised and hidden. Opening up our views, embracing new innovative ideas and most importantly working in partnership while respecting the different opinions of the groups involved in disability is no mean feat, but if achieved will bring disability to the forefront of society and invisible children will become visible, giving people with disabilities a chance and a choice to engage in society.

CONCLUSION

CBR is not about building programmes. It is about partnering for the long term, about cultivating relationships and about giving shape to a vision that encompasses human and environmental realities.

CBR is a tool for growth - personal and social - that finds its roots in the authenticity of equalitarian interactions. Reducing it to a mere contract or technical endeavor robs it of its life force and potential, and simply yields one more disillusion for people with disabilities. Remaining true to our philosophical lineage is still our best guarantee of success

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CHAPTER 5.

GLOBAL PARTNERSHIPS AND CBR

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SUMMARY

Global partnerships play an essential role in achieving quality CBR programmes which facilitate the participation and empowerment of people with disabilities, to achieve inclusive development. In turn CBR is an approach that can enable countries to achieve the much desired Millennium Development Goals, especially the goals related to the eradication of poverty and hunger. There are however, many barriers to such partnerships. This chapter discusses some of the barriers that are faced by people with disabilities in achieving partnerships and some of the pitfalls and obstacles to running CBR programmes in various African countries. It examines why global partnerships are very important to the development of CBR programmes, and gives examples of existing partnerships, how they work and what contribution they have made. It summarises key issues that might be addressed by emerging CBR programmes on how to get started and use partnerships to help them to achieve their goals.

INTRODUCTION

The World Health Organisation estimates that 400 million people with disabilities living in developing countries are among poorest of the poor. These people face several barriers in their families, communities and in society. These barriers prevent them accessing services and opportunities available to other citizens, in order to live fulfilled lives. They also often prevent them from participating in the partnerships essential to the development of CBR services.

Poverty alleviation in developing countries and genuine progress towards achievement of the Millennium Development Goals require that disability issues be explicitly taken into account and that people with disabilities actively participate in national and international economic and social development efforts. This process and result is known as ' inclusive development' (GPDD 2007). This goal is not achievable by any one group alone and partnerships are essential. For disabled people and their families to be part of this partnership, the social and environmental obstacles that marginalise and impoverish them need to be removed. This requires the collaboration of diverse partners. At the same time, national and international partners need to be sensitised on how this can be achieved. It is only when all members of the partnership are alerted to, and understand the perspectives of the other parties involved, that true global partnerships can be achieved.

BARRIERS TO PARTNERSHIPS

It is difficult to create partnerships and include people with disabilities in all aspects of life because of the barriers that exist. Examples include:

Environmental Barriers: These may be inaccessible public and private buildings, schools, offices, factories, shops, transport, information and communication systems. They shut out people with disabilities and are a constant reminder of their differences.

Institutional Barriers: These include expulsion, exclusion and segregation from key social institutions including education, employment health, law and recreation among others. Direct and indirect discrimination against people with disabilities prevents them from taking full advantage of these provisions. They are a result of

attitudinal barriers.

Attitudinal Barriers: People all over the world view and treat people with disabilities with prejudice in varying degrees. They regard them with pity, as incapable, inadequate, resentful, bitter, pathetic, tragic, abusive, aggressive, criminal, unhealthy, dependent on charity, costly for the society to support, a drain on the family resources, inferior or unemployable.

Economic Barriers: People with disabilities are disadvantaged when it comes to economic opportunities like access to loans, land and property, ownership of assets, business ventures and employment avenues.

Cultural Barriers: In most African countries people with disabilities are

looked at as a product of witchcraft.

All these barriers are realities and have to be addressed if partnerships, particularly development partnerships, are to flourish.

PITFALLS AND OBSTACLES TO CBR PROGRAMMES

CBR is a strategy within community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of people with disabilities (WHO, ILO, UNESCO, 2004). There is a strong relationship between disability and poverty. Poverty makes people more vulnerable to disability and disability reinforces and deepens poverty.

However, there have been so many CBR programmes mushrooming in various countries but with a lot of differences on areas of emphasis, approaches and models. Some programmes have not been holistic enough to be able to address the problems faced by people with disabilities. This may be attributed to lack of financial, human

and material capacity/support, on one hand, and technical support on the other. Development partners are therefore very crucial in order for our CBR programmes to be of best quality, holistic, efficient and effective.

The reasons that CBR programmes do not always fare well or make much impact are discussed below.

Participation: Most CBR programmes have involved communities at one point or another but have not made them participate fully in order to make the programme relevant to the local situations and therefore more effective. As a result they have failed to make realistic plans while taking into account problems, needs and resources available. This has led to lack of focus and unrealistic goals, inadequate policies on the part of governments and lack of ownership of the CBR programme by communities.

Funding: CBR is sometimes embraced for the wrong reason such as saving of money. It is assumed that CBR is a cheaper intervention option. However, the cost of training and supervising village-level workers (volunteers) is not being taken into account. Frequent turnover of volunteers requires constant commitment for training and re-training. This essential cadre needs not only training but also constant supervision; and it is supervision at this level that presents the greatest difficulty as well as costing a lot of money.

Training: Available skills within existing structures rehabilitate only a small

percentage of people with disabilities. However, the disabled population is growing. Therefore, there is need to tap under-utilised resources within the community.

It is against the background of barriers and challenges that we require sound CBR programmes. These programmes should be those that provide solutions which are compatible with cultures and conditions involving communities. They need to be able to engage many

disciplines to offer rehabilitation, alleviate poverty and achieve social inclusion for people with disabilities. To do this they need to be built on partnerships.

IMPORTANCE OF GLOBAL PARTNERSHIPS

Some people perceive 'Global Partnership' as being a means of extracting money from rich, idealistic, northern based agencies. However money from 'up north' is not partnership and it perpetuates dependency. African needs demand African solutions and partnership begins at home.

The question remains: why do we need global partnerships? Perhaps it is because only a small minority of people with disabilities is getting any kind of help to deal with their problems. Some of this is obviously due to limited resources but the situation is also affected by people not working together enough. NGOs do not talk much with each other, or with anybody else. There is not enough meaningful dialogue with organisations of people with disabilities, or with parent groups. Organisations of people with disabilities, especially at local and country level, seem fragmented, sometimes unable to present a united front and speak with one voice. Technical departments of government concerned with disability issues also rarely work together. If we do not work together in a participatory and coherent way, our impact will continue to be severely limited, and programmes will continue to reach only a few.

The Global Partnership for Disability and Development (GPDD) overall

objective (Draft charter – Final Version 2nd July 2007) is to combat the social and economic exclusion and impoverishment of people with disabilities and their families in developing countries. To achieve this objective, GPDD partners engage in public advocacy for inclusive development. They agree to work jointly and

individually to accelerate the integration of disability issues and people with disabilities into their own and other mainstream social and economic development policies, programmes and budgets.

Global partnership and networking therefore help to share resources, information on best practices and cross-fertilisation of ideas, which is very vital if indeed we are to succeed in our endeavours.

The primary means of action to advance the GPDD objectives include:

- Capacity building of DPOs and disability NGOs

- Knowledge sharing amongst public in general and development practitioners on disability and development issues.

- Research that aims to strengthen understanding about the two-way casuality between poverty and disability.

- Networking to encourage and assist other networks and partnerships, including UN agencies, to embrace inclusive development, to address disability issues and to include people with disabilities in their ongoing programmes. It also aims to foster and support national networks for disability and development in developing countries.

The above is in line with CAN (2008) CBR resolutions. CAN in itself is partnership and aims to promote:

Participation of DPOs and people with disabilities in development and implementation, use of policies, guidelines, PRSPS and PAPs

Mainstreaming of CBR and other disability programmes to embrace inclusive development approach and actively connect with other programmes that might be relevant to people with disabilities

Capacity building that will ensure effective service delivery of the CBR strategy- there is a pressing and continuous need to build capacity

Learning from others to enhance the development of CBR from lessons from other development programmes

Building alliances and networks at all levels that are essential for success of any CBR programme

Research in order to add to the evidence base of CBR to describe good practices, identify indicators, and develop instruments to assess the quality and impact of CBR programmes

CBR PARTNERSHIP – A CASE STUDY FROM MALAWI

Geographic and Economic Aspects

Malawi is a landlocked country that lies in south-eastern Africa, bordered to the west by Zambia, north and east by Tanzania, east and south by Mozambique. The country covers a total area of 118,480 sq. km., 24,400 sq. km. (20%) of which are water. The last census estimated the population of Malawi at 11,906,855 persons of which 4.2% were people with disabilities. Malawi ranks among the world's least developed countries. Its economy is based largely on agriculture which accounts for more than 90% of its export earnings, contributes 45% of gross domestic product (GDP), and supports 90% of the population.

In Malawi, people with disabilities, as in many other countries, face numerous challenges that result in their exclusion from the mainstream of society, making it difficult for them to access their fundamental social, political and economic rights.

Many make their way through life impoverished, abandoned, uneducated, malnourished, discriminated against, neglected and vulnerable. For them, life is a daily struggle in order to survive. Whether they live in urban centres or in rural areas, they share these common problems. They are largely excluded from essential services, they lack the protection of the family and community, and are often at risk of exploitation and abuse. The factors contributing to this situation are many and varied but include poverty, unemployment, and social isolation, environmental, institutional, attitudinal, and economic barriers.

Government commitment

The Government of Malawi through Malawi Council for the Handicapped[3] (MACOHA) is committed to maximise the provision of rehabilitation services to reach all people with disabilities in the country and therefore endorsed the CBR approach in its statement of development policies (1987 –1996), providing assistance to people with disabilities, the majority of whom live in rural areas. A CBR coordination committee was formed at national level, since this required multi-agency support and involvement.

The government sought technical and material support for a successful CBR programme since the idea was new in the country. UNDP/ILO came in 1989 and a baseline study was carried out in order to collect relevant baseline data on the problems and needs associated with rehabilitation of people with disabilities. This information was gathered in order to assist MACOHA in developing its CBR programme in an effective and efficient manner.

CHALLENGES

CBR programme is not holistic

There were some challenges though, such as laying too much emphasis on vocational skills and medical rehabilitation, as a result of previous studies from Ministry of Health. These revealed that most disabilities occurred in Malawi in children under the age of 4 years. The number of disabilities occurring at birth was also alarming.

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[3]   To be changed soon to a better name.

Most of these children had never been to school and faced livelihood problems as they grew up.

Poor Community Participation

There was poor community participation because in this case the programme was totally top-down. However even where community involvement was sought in the early stages of planning and subsequent implementation, there were problems such as:

- People not wanting to be involved due to failure of previous projects or difficulties in building up trust and confidence. This are linked to unkept promises and sometimes lies, from the past.

- High expectations, for example honoraria for CBR volunteers.

- Problems of conflict and inequality through political divisions, religion, culture and existing policies being in conflict with community based rehabilitation.

Lack of Adequate Resources

There was lack of resources leading to:

- Transport and communication problems.

- Low number of CBR workers.

- Inadequate referral systems.

- Insufficient training and supervision to maintain quality of rehabilitation.

- Problems of conflict and inequality through political divisions, religion and culture.

- Existing policies being in conflict with community based approach.

- Problems in extension to other districts or areas of a district

Other Problems

- Communities did not perceive the programme as theirs.

- There was little empowerment of people with disabilities to take a rightful role in the CBR programme.

- Problems in mainstreaming of disability.

- Negative attitudes leading to deprivation of rights of people with disabilities.

OPPORTUNITIES

Due to government's commitment, more national and international development partners have come in to support the existing efforts. This has been evidenced since the inception of the CBR programme in Malawi. There have been several partners, each with a specific area of focus that have given further financial, material and technical support that has made the CBR programmes more comprehensive, efficient and effective. The Malawi Government has made agreements with fellow governments e.g., those of Norway, Britain and Germany; memorandums of understanding between agencies like the Malawi Council for the Handicapped and the Norwegian Association of the Disabled, CBM, Sight Savers International and Action Aid International.

Through these partnerships, Malawi has had opportunities opening up as follows:

- Establishment of a Ministry for People with disabilities and the Elderly.

- Development of National Policy on Equalisation of Opportunities for Persons with Disabilities.

- Government acknowledging disability as a cross-cutting issue.

- Empowerment of disabled peoples' organization (DPOs) to greater levels.

- CBR study tours to get more ideas from other countries e.g., Eritrea.

- Networking with other countries through membership of CBR Africa Network (CAN).

As a result of these opportunities, a national CBR programme was launched which is looking into needs of people with disabilities holistically as stipulated in the National Policy on Equalisation of opportunities for People with disabilities. The policy enshrines human rights issues for people with disabilities, vis-à-vis:

- Prevention, early identification and intervention.

- Rehabilitation.

- Accessibility (to physical environment)

- Transport.

- Information and communication.

- Education and training.

- Economic empowerment.

- Social welfare and social protection.

- Self-representation and participation.

- Sports, recreation and leisure.

- Housing.

- Research and appropriate technology.

- HIV and AIDS.

ADVICE TO EMERGING CBR PROGRAMMES

Using the Malawi experience, emerging CBR programmes should:

- Take disability as a Human Rights and Development issue

and not charity (Road with Good Intention).

- Country studies on political approaches and government processes would be

very important in order for disability movements to lobby for policies that mainstream disability (Disability Friendly Policies). People with disabilities should participate in formulation of these policies because it is they that know their needs best. 'They are ones that know where the shoes pinch most.' It is a **must** to listen to what people with disabilities and their families say about their needs and problems, and gear our work to help meet those needs. This should include harmonisation of policies of the multisectors to that of disability, if any.

- Lobby for disability legislation to safeguard the relevant policies.

- Disability movements have to start from the grassroots by building capacity of people to defend and advance their interests.

- Through government commitment, seek development partners, national or international, in areas of technical, financial, material support.

- Lobby for representation of people with disabilities in various fora e.g., political.

- Develop national networks through formation CBR associations/National Resource Teams and any other similar networking mechanisms in order to streamline rehabilitation activities and services that are provided using the CBR approach.

LESSONS FROM CBM ON PARTNERSHIPS

CBM is one of the foremost CBR development organisations in the

world; it has a wealth of knowledge and experience in the CBR field. CBM believes that advocacy for inclusion and the rights of people with disabilities is a multi-layered strategy. It involves people working together at all levels i.e., project level, provincial, national and international. Learning from each other is very important. Strategic alliances of key stakeholders can bring about real change for the better.

Some of the lessons learnt over the last 25 years on top-of the above are summarised below.

- Start small and simple, and gradually expand and diversify.

- Start CBR with one or two core competencies – things you are good and credible at doing and to build upon them.

- Start 'nearer before far ', 'easy before hard', 'cure before care', and some would add, 'children before adults'.

- Remember, not all people with disabilities need to be rehabilitated.

- If CBR is not planned well, in a participatory way, involving all potential stakeholders, it will fail.

- Concentrate on what a person can do, rather than on what that person cannot do.

- Local Government Officials and other key community members must be involved from the outset and inclusion of people with disabilities in all aspects of community life is more relevant than the creation of 'special' solutions.

- Parents of children with disabilities and their potential groups and organisations can play a major advocacy role.

- A twin-track approach that combines direct service and advocacy

for inclusion and positive change is very important. Advocacy

without service has a reduced impact and service without advocacy also has a reduced impact.

- CBR is more effective where the population is accessible, and where there are good channels of information and communication.

- Availability of specialist back-up and good programme management are essential.

- No matter how good a CBR project is, it can only have limited geographical impact. Therefore, local government and national government must be involved, and committed, and partnerships must be forged.

- Good CBR programmes are owned and managed by the community itself, involving strong partnerships amongst local government, people with disabilities, parents, community leaders and professionals. Good CBR programmes mobilise the community itself to address the rights and needs of people with all forms of impairment, and are minimally dependent on 'outside' resources.

- The keys to inclusion, acceptance and equality are education and decent work.

- We must make the rights of people with disabilities a continuous political issue at all levels, and that is best by working together, instead of staying inside our comfort zones and pretending that we have all the answers.

- Never stop learning.

SOME EXAMPLES OF GLOBAL PARTNERSHIPS

WHO and the world CBR community

The recently developed global CBR guidelines, currently undergoing

field-testing is a good example of the power of a global partnership . A very wide range of people and organisations came together under the aegis of WHO, to develop the guidelines e.g., Governments, UN agencies, disabled people's organisations, professional bodies, local and international NGOs. This core group has the potential to crystallise into a global CBR alliance (Chapter 13).

The Global Partnership for Disability and Development referred to in this chapter is also another example, seeking to promote inclusive development and recognising that this cannot be done without facilitating diverse partnerships.

Vision 2020 is a classic example of an effective partnership which has succeeded through the International Agency for the Prevention of Blindness (IAPB), in reducing the prevalence of avoidable blindness very substantially in most middle and lower income countries.

CBR Africa Network (CAN) promotes partnership between all the players in the world of disability across Africa and as a result more information is available for sharing between the people concerned.

> 'Disability is not my task, your task, his task, her task but all of us together'. Anon

CONCLUSIONS

There is power in partnership and we must work together, if we are to reach the unreached and bring about a truly inclusive society. Global partnership can assist our CBR Programmes to have well laid out structures and strategies, and to be comprehensive enough to empower people with disabilities.

This will be through promoting the inclusion of disability issues and the participation of people with disabilities in policy and

programmes of their own and of governments or other organisations; encouraging, facilitating, joining and / or supporting coalitions of disability stakeholders at local, national and international level; undertaking research on disability, poverty and development issues, and working to improve the quality, quantity and comparability of disability data; engaging in capacity building of personnel of local government, non-governmental and disabled persons' organizations; and finally, assessing and evaluating various strategies and institutional approaches to mainstreaming disability in economic and social development (GPDD).

When this is done, the main goal of achieving inclusive society will have gained major strides. This will lead to policies, programmes, practices, resources, advocacy and corporate commitment, all for inclusive development in which people with disabilities are included and participate actively in national poverty reduction and economic development efforts.

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CHAPTER 6

CBR experience in Francophone West Africa: Burkina Faso, Ivory Coast, Niger and Togo

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SUMMARY

This chapter reviews the development of rehabilitation services through Community-Based Rehabilitation (CBR) programmes for disabled people and their families, in four Francophone West African countries. The descriptions illustrate the various challenges that each country faces and the initiatives they have taken to meet these challenges. In spite of all the reassuring political declarations and the commitments made by different governments, particularly through the adoption of the UN Convention on the Rights of People with Disabilities, many CBR programmes in the continent do not go further than the pilot stage. So, people in a disabling situation continue to live in poverty and are generally reduced to begging and face other dehumanising frustrations. However, this general scenario which is characterised by limited achievements, illustrates that CBR experiences within the same West African group of countries can present different characteristics. The review seems to show that these characteristics are related to the interest and involvement of the different parties, namely governments, programme managers, local communities, families of people with disabilities, and above all, people with disabilities themselves and their organisations. The fact is that in

*all African programmes, there are political, sociological, cultural and economic considerations, which will be highlighted in the "presentation of the experiences of Francophone West Africa countries". As part of this chapter, we will consider four CBR programmes implemented in **Burkina Faso, Ivory Coast, Niger and Togo**. The summary of the different CBR experiences in French-speaking Africa presented in this chapter makes no explicit comparisons, but rather places these experiences side by side.*

BURKINA FASO

Physical disability rehabilitation and CBR

The current health policy in Burkina Faso is based on primary health care. Nevertheless, we notice that rehabilitation is not taken into account in the preparation of the different development programmes in the health sector. Thus ignored by government, responsibility for rehabilitation is assumed by private organisations. As an illustration of this, only 4 of the 44 rehabilitation centres are publicly owned. As a result, CBR remains experimental and is managed by associations. Burkina Faso neither has a national policy nor a national community-based rehabilitation programme.

There are only pilot CBR projects developed by the private sector in rural areas. There are also sector-based CBR programmes exclusively devoted to education or vocational training. On the whole, these initiatives face functioning difficulties related not only to the lack of human resources, but also to the inadequacy of financial resources. Finally, these various programmes have hardly any functional relations with each other and therefore their work is confined to their geographic area.

Perspectives

The development of CBR in our country requires:

- Advocacy towards political and administrative authorities to integrate this strategy fully into our national strategy for the

development of the health sector. This action also has to be aimed towards specialised UN institutions so that they support local technicians in the preparation of our action plans.

- The development of human resources: at present, Burkina Faso lacks rehabilitation personnel. There are only two rehabilitation doctors for the whole country. As the implementation of a strategy requires preparation, we think that it is time we invested in the training of rehabilitation staff.

- The development of a national CBR programme: rehabilitation is not considered as a priority by the administration, and it would therefore be relevant to set up a national CBR programme to address the ever increasing needs in rehabilitation care.

- The mobilisation of financial resources: as we know that the third-party payer system in still embryonic in our countries and that people in a disabling situation count among the poorest inhabitants, we will have to find funding sources for our different rehabilitation projects.

Conclusion

Rehabilitation in general and CBR in particular, is in a distressful state in our country. It is essential to undertake substantial information work for a better knowledge of this strategy in our country. Finally, let's stress the need for specialised UN institutions like WHO, to become more involved in the development of a national health policy for a better consideration of CBR.

IVORY COAST

Activities

In 1990, the collaboration between Ivory Coast and funding bodies led to the creation of a CBR national programme. The programme was placed under the authority of the Ministry of Social Affairs and Persons with Disabilities. According to the terms of the protocol of agreement, after an experimental phase, the Ivorian government was to find the necessary means for its perpetuation. Unfortunately, due to the economic crisis engendered by the fall in the prices of raw materials and the CFA currency devaluation, the programme was stopped in 1996 and people with disabilities were left to their own devices. To respond to the vacuum created by this interruption, NGOs and disabled people's organisations in collaboration with the Department for the Promotion of People with Disabilities, set up a programme for the individual management and integration of disabled children in mainstream schools, and for access to health services and vocational training. The main activities essentially consist of management actions at the educational and socio-economic levels:

Educational management

Unlike certain countries where the education of all children is the duty of the Ministry of Education, in Ivory Coast, the educational management of disabled children is delegated to the Ministry of Social Affairs. Since 2003, with the implementation of a pilot inclusive education programme, awareness-raising among the general population and especially among parents and teachers, enabled the enrolment of many more sensory disabled children (deaf-mute and blind) and children with learning difficulties in mainstream schools. Besides, the collaboration between the Department for the Promotion of People with Disabilities and the Ministry of Education enabled the training of fourteen teachers for the management of children with specific educational needs.

Socio-economic management

In this field, the experience of the Christian organisation for the promotion of blind and low-sighted persons in Danané (OCPAM)

is a successful example of Community based rehabilitation. With the technical support of the Department for the Promotion of People with Disabilities, this organisation has created a programme for the socio-economic integration of the blind living in the Department of Danané, in the west of the country. For this programme, the Ministry in charge of people with disabilities has provided a three-year training for a hundred teachers in Braille and other techniques. They go from one village to another to teach literacy to blind people. The blind people who have been taught gather together in "village centres", where they engage in income-generating activities (sometimes in collaboration with non-disabled persons).

Outputs

The collaboration between the Department for the Promotion of People with Disabilities and NGOs in general and OCPAM in particular, has made it possible to achieve encouraging results. In fact, before the armed crisis that the country is going through, this organisation had four agropastoral farms (breeding of snails in Yiealeu, breeding of chicken in Danané, Man and Issonneu, beekeeping in Bouagleu); it also had a 4-hectare market garden in Issonneu, a 15-hectare rice field in Mahapleu and was equipped with power-driven pumps, tractors, etc. It used to sell large amounts of subsistence crops and also quarried for and sold sand (an appraisal in underway).

Difficulties

There are difficulties in the management of disabled children at various levels:

Facilities: there is a lack of specialised centres: there are only two public specialised institutions for children with sensory disabilities. Both facilities are in Abidjan (in the south).

Educational supervision: there is a lack of qualified personnel (special education teachers).

Equipment: the existing centres do not have any educational material.

Legal level: there is slowness in the signing of the implementing orders of the 98-594 Act of November 1998, in favour of people with disabilities.

Social level: negative social attitudes constitute a major obstacle to the integration of people with disabilities.

Perspectives

In order to revive the programme that was stopped, a feasibility study for a national programme has been submitted to the national authority. The institution has approved it and it could soon become a reality. This will result in the creation of a new programme, the project paper of which is in preparation.

Conclusion

In spite of all these difficulties, it should be noted that such a political will in favour of people with disabilities had never been experienced before in Ivory Coast. Yet, this strong political will is likely to falter for want of financing, and disabled citizens might remain in their situation of extreme poverty.

NIGER

Introduction

To date, Niger does not have a national CBR programme. However, there are various organisations that care for people with disabilities (associations and NGOs), and they have come together in federations and networks. The Community based rehabilitation project for blind persons and other persons with disabilities, named by its French acronym as "PRAHN", is the only organization that implements CBR. PRHAN is the fruit of a convention signed between Christoffel Blinden Mission (CBM) and the National Union of Blind Persons

of Niger (UNAN) in 1989. PRAHN is under the legal guardianship of the National Union of Blind Persons of Niger (UNAN) and is mainly financed by CBM. Under the leadership of the Ministry in charge of public health and the control of endemics, the blindness control activities are conducted by many stakeholders. They include the National programme for the control of blindness in Niger (PNLCC) that coordinates all the activities related to ophthalmology, Helen Keller International (HKI), the International Trachoma Initiative (ITI), the Agency of African Muslims, the Makka Ophthalmic Hospital, etc.

Ophthalmic activities for the control of blindness in Niger

In order to conduct its activities in Niger, UNAN/PRAHN has signed a three-year draft agreement in ophthalmology with the Ministry in charge of public health and the control of endemics. The agreement defines the conditions for the implementation of ophthalmology activities by PRAHN.

Mobile service team

The mobile service team is managed by an ophthalmology technologist who operates on cataract. It is made up of six workers, namely three nurses specialised in ophthalmology, a certificated nurse (currently under training), a supervisor and a driver. The team carries out an average of ten surgery campaigns and operates on a thousand patients each year (approximately 90% of the surgical procedures concern cataract). It performs approximately 20% of the cataract procedures of the country each year. It is supervised by an ophthalmologist appointed by the National programme for the control of blindness in Niger (PNLCC) in accordance with the agreement signed between PRAHN and the Ministry in charge of public health and the control of endemics. In their daily activities, the supervisors undertake screening and raise the awareness of people in a disabling situation, including those with visual

impairment. They treat conjunctivitis with 1% tetracycline pomade. They also refer patients with more serious conditions to specialised centres.

Prevention

The preventive measures will be organised around the observance of hygiene rules (trachoma), and the early detection and appropriate management of all cases. The earlier the case management, the more we can avoid blindness.

A large-scale awareness-raising campaign is necessary to prevent affected persons from giving themselves up to the "*Sidibé*". Prevention is the most important phase, as it often makes it possible to identify people with disabilities, especially those who have critical needs and are usually hidden in their communities.

Besides these direct activities, there are prevention activities that can be considered as indirect, namely the construction of community wells to allow people especially in rural areas, to have enough clean water and better hygiene.

<u>Information/Communication/awareness-raising</u>

Information and awareness-raising have to be conducted on a regular basis. Links have to be established and maintained with administrative, traditional and local authorities, because PRAHN supports communities but does not replace them.

Case management activities

Concerning the management of cases, PRAHN intervenes at all levels: health, physical and socio-economic rehabilitation, and education.

To date, the programme has provided 24856 medical consultations. Depending on the results, age and the environment of the patients, the following services are proposed:

- If the patient is very young (under 7 years old), early stimulation activities reflecting daily life situations are proposed to the parents.

- If the patient is 7 years old, they propose enrolment if there is a school in the area.

- If it is an adult, they propose vocational training in a field adapted to their disability, to allow them to have a certain level of independence.

- If it is an old person, they propose mobility guidance and income-generating activities either individually or within a group.

These consultations are assured mainly by the ophthalmology team that travels regularly (approximately 20 days per month) to raise awareness, consult and treat all ophthalmology cases throughout the country. The team also provides post-surgical follow-up. These activities are carried out under the technical supervision of an ophthalmologist appointed by PNLCC.

Since 1999, emphasis has been laid on income-generating activities for people with disabilities (particularly disabled women) organised in groups in Niamey as well as in rural areas. In 2004, 425 people with disabilities including 258 women received our financial support and technical guidance; 50% of them, i.e. some 213 people, were blind. In total, as part of the rehabilitation activities from 1974 until now, some 30 000 people with disabilities and their families have received economic support.

Education is a very important activity for us, and we manage to identify and send disabled children, including blind ones, to specialised educational institutions. Since the last few years, it is PRAHN and its network of workers that provide pupils for the Soli Abdouramane School. It is also PRAHN that, thanks to its commitment, has brought the Ministry of basic education and

literacy tuition to open five inclusive classes for blind students in the interior of the country. The determination of PRAHN enabled the creation of a dynamic partnership between MEBA/PRAHN and UNICEF (one of the major backers of this activity in Niger). We started by organising selective activities in 2000 to train teachers for the blind, and then we went on to set up a national strategy for specialised education, which is about to be validated. This strategy is going to be the framework for all the actions regarding specialised education in Niger. Besides, we also promote the inclusive approach as a replacement to the traditional institutional approach. We believe that this can allow a greater number of blind children to attend school.

Activities in physiotherapy and orthopaedics

The ten supervisors identify people with various needs such as physical disability rehabilitation, orthopaedic fitting, surgery, etc. Then, the assistant physiotherapist who is responsible for the physiotherapy/orthopaedics section examines them and works out an Individual Rehabilitation Plan for each case, in collaboration with the supervisor and the family of the patient. The patients who need physical disability rehabilitation only, are followed up in their families by the supervisors. People with disabilities in general and children in particular in need of surgery and/or fitting, are transferred to Niamey. Orthopaedic surgery is done at the National Hospital of Lamordé, and the orthopaedic devices are made at the National Hospital of Niamey. Prior to the hospitalisation and/or pending the delivery of the devices, the children are housed at "Hope House". During their stay in Niamey, they receive food. Fees for their return trip are also paid. When they leave the hospital, the children return to their respective families and are followed up by the PRAHN supervisors with the help of the parents. For physical disability rehabilitation activities, PRAHN does not ask the families to give a financial contribution at present. However, for surgery

and orthopaedic fitting, PRAHN requests a contribution that varies according to the type and cost of the service provided. The average amount requested from patients or their parents is 30 000 CFA francs for surgery (an orthopaedic surgical procedure costs 300 000 on average in public health centres). Each month, a supervisor can follow up an average of 30 children who need physical disability rehabilitation, orthopaedic fitting or surgery.

STRENGTHS AND WEAKNESSES OF THE PRAHN CBR PROGRAMME

Strengths

The programme is largely based on the specialised services it provides on a regular basis. As far as PRAHN is concerned, we have the following advantages:

- Good collaboration between parents, the different service provides (health workers, social workers, teachers) and the workers of the programme

- Good relations between the families of the children and the reception facilities

- Training of the parents in the communities on the rights of people with disabilities regarding education, training, employment, health, etc.

- Better knowledge of the situation on the ground and the target group

Weaknesses

Special attention should be given to the following aspects:

- Lack of financial resources and equipment

- Illiteracy of the target group, i.e. people with disabilities and their families

- Lack of information in the target group

- Long commuting due to the large size of the country

- Weak involvement of political authorities in taking charge of people with disabilities

TOGO

Introduction

A detailed classification of people with disabilities reveals four major groups:

- Persons with sensory disabilities: 37% (27% of blind, 10% of deaf-mutes)

- Persons with motor disabilities: 31% (paralysis of lower and upper limbs, amputees)

- Persons with mental disabilities: 7% (mentally deficient persons)

- Other: 25% (multiple disabilities, epilepsy)

Given the difficulties faced by this part of the population, Togo has undertaken a programme to support them and improve their living conditions.

Created in September 1999, the National Community Based Rehabilitation (CBR) programme in charge of the rehabilitation and prevention of incapacities and trauma in Togo is under the supervision of the Ministry of Health. It covers 5 regions, is implemented in 16 departments or prefectures, 99 villages, and covers 23 674 people. In addition to the economic support for persons with disabilities, the programme has an "Inclusive Education" component. Initiated with the financial support of the government, the programme received funding from the WHO from 1999 to 2002. Since 2002, Handicap International has taken over,

as the government no longer finances the programme. The activities are part of the community development process for the prevention of incapacities and for rehabilitation, equal opportunity and the social integration of people with disabilities. The programme is based on the principle of participatory development, an innovative approach requiring the mobilisation of human, material and financial resources for a better social integration of people with disabilities.

CBR activities implemented in Togo

Preparatory and awareness-raising activities on disability

The aim of these actions is to facilitate change in people's attitudes and promote a positive attitude towards people in a disabling situation: this is essential if we want to guarantee equal opportunity for people in a disabling situation in their own community. The activities cover:

- The study of disabling situations (census, prevalence survey, etc.)

- The training of the different stakeholders: Community based rehabilitation workers, people with disabilities and their circle, volunteer workers, elected officials, teachers, health workers, managers in the private sector etc., to improve their perception of people in a disabling situation

- The early detection and primary prevention of disability

- The development of outreach solutions (at the community level) for the provision of basic care: simple rehabilitation processes, handling and nursing, simple technical aids made with locally available material. These activities facilitate adaptation to the environment, the development of functional independence of persons with disabilities, and the improvement of the daily care that people provide for them. In addition, the national programmes and the Togolese Federation of Disabled People's Organisations broadcast programmes in the media to raise the awareness of the general public on the skills and needs of the people with disabilities. It is also necessary to improve access to referral centres for more complex problems.

Support activities

The support activities include methods, approaches and techniques that can facilitate the professional, economic and social integration of persons in a disabling situation:

- Actions for the promotion of specialised or inclusive education (primary, secondary and higher education).

- Actions for the promotion of vocational training and professionalisation (in mainstream and specialised environments, through support for micro projects and micro credit, etc.).

- Actions for better access to sporting, leisure and cultural activities (specific laws, financial support, construction standards, disabled persons' card etc.).

Strengths of the CBR programme

The programme is inspired by the following positive factors:

- There is a national law for the protection and promotion of people with disabilities which has been adopted but not yet enacted.

- The national programme promotes the empowerment of people with disabilities.

- Committed support from partners mainly Handicap International and Christoffel Blinden Mission.

- Existence of an associative momentum in the field of disability.

- Material and moral support of local authorities for the activities of the programme.

- Inclusive education success stories.

- Commitment and availability of stakeholders who work to achieve better living conditions for people with disabilities.

- Existence of a national policy for the prevention of disabilities and for rehabilitation.

Weaknesses of the CBR programme

In spite of these undisputed assets, there are some weaknesses, namely:

- The non involvement of local Disabled People's Organisations in the implementation of the programme.

- Lack of trained and qualified personnel in the rehabilitation sector.

- Lack of funding for the implementation of the programme.

- CBR workers are volunteers and cannot ensure proper continuity of activities.

- Lack of a section in charge of specialised education in the education department.

- CBR provides only partial coverage of the country.

In addition to these difficulties, there are constraints like social and cultural inertia, the unfavourable socio-economic situation that generates poverty and leads to or aggravates the degradation of solidarity in the community.

Prospects and challenges of the programme

There are many opportunities, but the situation of people with disabilities is likely to become more difficult, if no measures are taken to bring together the efforts of all the stakeholders and promote

the full participation of people with disabilities.

It is therefore crucial to:

- Promote the rights of people with disabilities through the enforcement of existing laws, the modification and/or enforcement of legal instruments and international recommendations.

- Develop the operational capacities of organisations.

- Endow the national programme with equipment and logistical means.

- Guarantee equal opportunity for people with disabilities through support and the promotion of preventive, curative and functional care.

- Meet the needs for special education.

- Take into account the needs relating to training/employment and professional integration in the community.

- Create a framework for collaboration between the different agencies and partners.

- Improve the quality of the services provided.

- Develop the capacities/skills of the field workers through training, retraining, study trips, motivation of PDR workers, and the availability of appropriate documentation.

- Strengthen social mobilisation through the creation of communication tools and the development of awareness raising strategies.

- Inform professionals (disability specialists as well as specialists in other domains) so that they use their skills not only to "perform" their duties, but also to advise persons with disabilities and their families and make them become real stakeholders of the network. To this end, the activities

undertaken at the community level should be considered as part of the rehabilitation process.

- Create a positive mindset towards persons with disabilities and allow them to be part of the development process in their community.

- Promote equal opportunity by facilitating access to services in the living environment of people in a disabling situation, because accessibility is a requirement for the integration of people in a disabling situation.

CONCLUSION

Although the CBR approach might be suitable for developing countries a lot remains to be done to reach full community participation and lasting stakeholders' commitment. The method of implementation and its objectives need to be adapted to the social, cultural and economic context of each country. However, it was found to be hard to bring rehabilitation professionals at community level to provide advice and skills training to disabled people and their families. Another critical aspect that is needed is to develop a more positive people's attitude towards disabled persons by allowing them to be actors in the development of their communities. Facilitating physical accessibility to various services of daily life remains a serious challenge for the majority of disabled people. This should be a priority requirement permitting their social integration.

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CHAPTER 7

COMMUNITY BASED REHABILITATION AND FAMILIES IN CRISIS

Maria Kett, Martha Geiger and Marieke Boersma

SUMMARY

This chapter is based on three different aspects of the ways in which community based rehabilitation (CBR) could be used to ameliorate situations for 'families in crisis'. The three aspects complement each other as they explore from different perspectives how crises in the broadest sense pervade and affect individuals, communities and nations and how these are interlinked.

The chapter starts by elaborating on the differing forms of crisis; the effects these can have; and what measures can be taken to try and protect oneself from them. Much of the discussions and literature on disability and crisis situations focuses on large scale emergencies or situations of violent conflict. This is of course an important focus; however, this chapter will take a slightly different view and explore issues, problems and solutions for very personal crisis – or what can be called 'families in crisis'. This perspective engages at community level, contextualising problems in Ethiopia and South Africa, as well as offering some possible solutions.

INTRODUCTION - WHAT IS A CRISIS?

Crisis situations vary from the personal to the political, and can be on a local or a global scale. The effects often extend beyond the immediate scope, and the ramifications can be enormous. Most crises can be divided into broadly slow or rapid onset, and arise from a response to an internal or external 'shock'. Often, these can interlink and affect each situation.

GLOBAL LEVEL CRISIS

This list is not exhaustive, but some of the situations that can precipitate national or global crisis include:

- Failure of states to protect citizens (including situations of violent conflict).

- Resource scarcity (famine, drought).

- Epidemics.

- Disasters (resulting in loss of homes, livelihoods).

- Large scale accidents (i.e. industrial).

- Population displacement (often a result of one of the above).

Disasters and emergencies have an enormous effect on communities and families, which may continue for many years after the event. These include:

- Separation/loss of head of household.

- Displacement.

- Trauma (physical and psychological).

- Lack of resources.

- Lack of access to facilities (including to employment, education, health care).

- Injury/ill health.

- Poverty.

In the contemporary geopolitical climate, it is rare to find a 'simple' crisis due to increasingly complex political relations at national and

international level. Recent research into hazards and vulnerabilities has demonstrated that there are a number of variables that affect the outcome of disasters. This is illustrated by the 'Pressure and Release' model (Blaikie et al, 2004), which demonstrates the multifaceted aspects of risk and vulnerability to such 'shocks' or crisis. A number of factors can mitigate the effects of personal and humanitarian crisis on people and populations. These include: awareness and potential protection from external shocks; preparedness; living and working conditions; access to healthcare; insurance and good health and nutrition. At a national level, they include political will, national and international relations, pre-existing resources and infrastructure.

However, it has been argued that poor people themselves rarely participate in vulnerability assessments, therefore risk behaviour is often assumed, and leads to the identification of wrong or irrelevant risk reduction measures (Heijmans 2001: 10). The same can be said about disabled people in many situations of potential and actual crisis. Research has shown that disabled adults and children continue to be among the most marginalised and excluded within communities. Within many programmes focusing on emergencies, disabled people are often ignored, or many assumptions are made about their capacities and capabilities (Kett et al, 2005). One of the most frequent assumptions is about degree of vulnerability and leads to a welfare-based rather than rights-based approach to interventions. Recent, more nuanced work on resilience enables each member of a community to be treated as having personal capacity and ensures that each member of the community is included in planning, preparation and response plans. It also means that those seen as 'most vulnerable' have the chance to identify the barriers that cause or maintain their 'vulnerability'. These can include:

Social

Society, the environment and context are the major factors in a disabling situation. There remains a widespread lack of knowledge regarding the social model of disability, particularly in disaster and emergency settings.

Cultural

In many cultures, disabled people are stigmatised due to ignorance, fear and misunderstanding. Many experience physical and sexual abuse, abandonment and separation from families. Again, this can be exacerbated in emergency and crisis contexts.

Physical/environmental

This includes access to public buildings such as schools, libraries and workplaces; but also access to appropriate tools and resources to enable equal opportunities to employment and participation. It has been demonstrated that costs of rebuilding in an accessible way, are significantly reduced if included as part of an initial package rather than added on later.

Attitudinal

Attitudes of particular concern are related to parental and social expectations. Disabled adults and children and their families often experience social isolation. Agencies and organisations working in the area of disasters and emergencies may (intentionally or unintentionally) exclude disabled adults and children from their programmes due to their lack of visibility.

Poverty

Poverty is both cause and effect of disability and may result in a lack of education, unemployment, malnutrition, lack of resources, dangerous living and working conditions, limited access to healthcare and subsequent increase in diseases and ill-health, lack of maternal

and child health care, poor hygiene and sanitation and an overall lack of information about rights and entitlements.

CBR AND CRISIS SITUATIONS

Most international and national organisations and non-government organisations now utilise a rights based approach in both emergency and longer term development interventions. Crucial to this is the role national and international legislation plays, particularly the recent UN Convention on the Rights of People with Disabilities (UNCRPD)[4] specifically Article 11 on situations of risk. As a result of the UNCRPD, DPOs are increasingly involved in decisions made about disabled peoples' lives. However, a number of groups are often excluded from these discussions: adolescents, children with learning disabilities as well as parents of disabled children, disabled mothers, and child-headed households. Much more work needs to be done on how to include these marginalised groups in CBR work, but the following examples demonstrate some tentative ways in which this is being done.

What can community based programmes (CBR) do to ameliorate these situations? There are a number of assumptions that have to be challenged when considering CBR in crisis and emergency situations. The first of these is whether CBR can be a useful approach in an immediate phase of a crisis. There are a number of benefits of a CBR approach in the initial stages of an emergency: The first of these is its outreach capacity, to use CBR approaches to focus on immediate needs, including medical care and rehabilitation. If there is already a CBR programme in place, local CBR workers will have knowledge of disabled people's locations, needs and support structures. However, this raises questions of what structures were already in place, and the scale of the crisis,

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[3]   http://www.un.org/disabilities/

and the scope of the CBR programmes. If there was not already a programme in place, CBR approaches can be initiated early on and be fully included in the wider response.

There are few country examples of any multilateral cooperation between NGOs or donors doing CBR projects on a countrywide scale in crisis-affected countries. An issue for CBR approaches in general has been the need to scale up to national-level (or country-wide) service provision. There have been many pilot projects, but these often lacked resources for training and personnel and are rarely successfully scaled-up, particularly challenging in resource-poor environments when other services are likely to be prioritised. There is limited evidence that CBR is any more 'cost-effective' than any other method of delivering services, especially in conflict-affected areas. Costs of course depend on who is implementing the programme, and multi-sectoral collaboration remains difficult.

A second assumption is that of 'community'. In many crisis situations, communities - and families - have been destroyed. Moreover, as the following examples demonstrate, there may not have been a reliable community structure to facilitate inclusion in the first place. What replaces these structures before, during and after a crisis, and how can a CBR approach tie in with this?

It has been established that there is a need to ensure that governments in conflict and disaster-affected countries both have and provide the resources needed for inclusive community development (Boyce 2000; Giacaman 2001). This unproblematic conception of community and family involvement means that often they are assumed to be homogeneous and harmonious, whereas they are often too poor and/or over-burdened to play active roles. Many of those who undertake the often low-paid or voluntary work are women and this merely adds to their burden. However, if there is limited state acceptance of CBR programmes, then involving family and/or community members may be the only way to ensure

sustainability of CBR programmes. The following example from the townships in South Africa gives credence to this.

A third assumption is that of homogeneity of communities, including disabled people themselves. It is important to acknowledge diversity and difference within this group. Acknowledging diversity, broadening the concept of community, and ensuring the different interest groups, agendas, and power structures are incorporated into programme planning can ameliorate divisions. It is vital to work with DPOs at community level, in order to engage with relevant issues and engage disabled people themselves in the work. Care should be taken to ensure that those without any networks – for example, children or single parent families - are also included in programmes.

But what are the alternatives? There is of course a fine line between inclusion out of choice and out of necessity. For example, in resource-poor environments, getting a disabled child into a school does not necessarily equate to inclusive education. Should CBR be seen in opposition to 'mainstreaming' or other forms of service provision? Perhaps it is more useful to see all of these approaches as a continuum of service provision from self care to family support and services available in communities, to specialist service provision - a 'network of services'. This acknowledges the need to maintain a balance between specialist support and assistance to prevent marginalization and community level support and approaches. Through this, there is also the potential for specialist services to become a resource for communities.

In moving towards an inclusive framework, mainstreaming must ensure that the needs of the whole community are taken into consideration, from the communities' own perspective, plus the need for enabling environments, legislations and other resources (World Bank 2005). There are of course many difficulties in implementing programmes in crisis situations (including security, infrastructure,

and human resources). But in any of these circumstances, recovery must include psychosocial rehabilitation, community based rehabilitation (CBR) projects, education programmes for families and communities, and microfinance initiatives to help promote integration and rehabilitation.

DISABILITY IN CRISIS SITUATIONS

So, how can opportunities be utilised and resilience increased for families in crisis situations? To mitigate vulnerability, families need the 'Three Cs': capacity, capabilities and capital. But underlying this is a need for another 'C' - community cohesion. One way to promote this is to ensure that everyone is aware of each other's strengths and weaknesses so communities can work together. Ensuring disabled peoples' organisations (DPOs) and disabled adults and children are included in all levels of planning, mitigation, relief and recovery programmes is of equal importance. DPOs should work to improve their links with other civil society organisations (CSOs), as this will also help foster dialogue between DPOs and international and national agencies involved in processes.

It is important to remember that though a crisis may present a danger, it can also be an opportunity - for example, to renew, regenerate and to develop skills and strengths. It is also important to highlight that many of the crises that affect disabled people are common problems for everyone - though they may be attenuated for disabled people. However, these can also be turned into opportunities. During the brutal war in Sierra Leone, disabled people were often left behind by families fleeing rebel attacks, and excluded from international assistance. Motivated by necessity, many disabled people formed themselves into self-help groups that later became DPOs, often with a strong emphasis on livelihoods. It is vital to build these networks up in the transitional period. Another key

area is to engage disabled people themselves, in wider development/ reconstruction agenda, and vice versa.

HOW CAN A CBR APPROACH BE EFFECTIVE?

However, CBR should not focus solely on making people economically productive. There are a number of practical issues that may have to be resolved, such as a child of a disabled parent, who may be the family's only wage earner, being engaged in remunerated work and not attending school, or how easy is it for a parent to attend a training programme about a CBR programme, if they are the sole care giver for their disabled child?

Of course, there are many other benefits of inclusion. It promotes decision making capacity, self-esteem and confidence, which in turn has positive impact on communities, and may even have a peace-building function in conflict-affected countries as programmes promote equality and integration of the poor and marginalised (Boyce et al 2002). This in turn, may contribute to the promotion of security, reconciliation and reintegration in conflict-affected countries.

So far, the chapter has focused on a generic overview of CBR, particularly in emergency and crisis situations. It should be pointed out that more recent works – including the World Health Organisation's updated CBR guidelines, take care to differentiate between the emergency phases of any crisis, and the shift into longer term relief and development. The examples of violent situations in Ethiopia and South Africa that are given below focus on what can be termed 'non-emergency' crises and discuss how a CBR approach could be effective in mitigating the potential of such crisis on families.

CBR APPROACHES TO VIOLENCE AGAINST CHILDREN WITH A DISABILITY IN ETHIOPIA

Globally, there remains limited data about violence against children with a disability; however, in many countries, disabled adults and children are regularly targets of violence and abuse. UNICEF report that children with a disability are more vulnerable to violence than other children for many reasons (Groce and Peaglow 2005). Reports from CBR field workers in Ethiopia indicate that violence against children with a disability is widespread across the country, yet there is very little information available about this apart from a global UNICEF report (Groce and Peaglow 2005). One local study demonstrates how expressions, attitudes and perceptions of the community about disability, creates stigmatisation of people with a disability in Ethiopia (Teferra 2005). Furthermore, entrenched gender disparities within Ethiopian society make girls and women with a disability even more vulnerable to stigmatisation and violence (Teferra 2005; Mohasen 2006).

The idea that children can be social actors is still relatively new, though the numbers of researchers doing research with children has increased (Christensens 2000). In Ethiopia, as in many other countries, people were surprised that researchers wanted to talk directly to the children. In particular, some parents, carers and even people from other organisations, were surprised that children with disabilities could be directly spoken to and asked questions, as there is often an assumption that these children cannot speak for themselves or have no idea about the answers to the questions asked.

In Ethiopia, CBR is being utilised as an approach to the rehabilitation and integration of children with a disability. CBR workers are recruited from the local community and trained to work in their own communities; this can be problematic if dealing with issues such as child abuse, and also raises questions about level of training and experience. At the moment, there is almost no

knowledge about the nature, if any, of interventions done by CBR workers to stop and prevent the violence, or regarding the effectiveness of interventions to prevent or stop the violence. According to Finkenflügel, there has been no research on the effectiveness of using lay people from the community to become CBR workers (Finkenflügel, 2004). This study here represents an attempt to understand the interventions and effectiveness of CBR workers, in a complicated matter like violence against children with a disability.

Despite the fact that the issue of violence against children with a disability, had been raised several times by CBR workers in training sessions of the CBR network in Ethiopia, CBR programmes did not really work on the topic nor have any particular support system for the fieldworkers who had to deal with the problem of violence on a daily basis. The research presented here sets out to examine the perceptions, experiences and reactions of children with a disability, their families as well as CBR workers, to the issue of violence against children with a disability. It will also explore some possible interventions, and is based on research undertaken in the field by one of the authors.[5]

THE SITUATION IN ETHIOPIA

Ethiopia is surrounded by Sudan to the west, Eritrea in the north, Djibouti and Somalia in the east. Three of these four countries are either hostile to, or are at war with Ethiopia. There are also a number of civil wars going on inside Ethiopia and the surrounding countries. All Ethiopian borders have refugee camps with refugees from the surrounding countries. It is among the poorest countries in the

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[5] The material presented here is based on work undertaken by Marieke Boersma towards a Masters Degree in Medical Anthropology and Sociology of the University of Amsterdam Degree.

world. Infant mortality rates at birth are 112 per 10 000 and 169 per 10 000 children do not survive their 5th living year. According to a recent WHO report, indications are that disability prevalence rates are high due to these poor living conditions (WHO 2006). Three quarters of the population has no access to clean water or good sanitation and consequently, the chances of, for example; developing blindness from trachoma or other disabling diseases are much higher in such conditions. Drought, displacement and armed conflict also increase the chances of becoming disabled through injury or communicable diseases. Around three million people are estimated to be affected by AIDS; with a further 5000 people newly diagnosed each week (WHO 2006). As with many other people with disabilities, people with AIDS are enormously stigmatised in Ethiopian society. There is also evidence of many other poverty-related conditions which can lead to impairments, including communicable diseases such as polio, possibly due to war-related displacement.

Though education enrolment rates have risen in the past few decades, they remain low: 57.4% of youth between the ages of 15-24 years in Ethiopia can read simple sentences that are related to their daily life (Teferra 2005). Access to education for disabled children remains patchy and sporadic and the data is somewhat out-dated. According to the Ministry of Education, in 1997 there were 2276 children with disabilities going to school - either in special schools or classes. Based on disability prevalence rates, this meant that only 0.33% of the children with a disability in Ethiopia had access to school (Teferra 2005). There are some government schools providing special needs education in the capital and some churches provide schools for the deaf, blind and those with learning difficulties. The Ministry of Education has undertaken some initiatives to introduce inclusive education in the country. In 2006, they published their Strategy on Special Needs Education, which encourages inclusive education in all schools in the country. From

having two schools that train teachers in special needs education, the number has increased to six, which train teachers from diploma level to Masters level.

People with a disability in Ethiopia face a great deal of stigma and many challenges. Non-disabled children and adults from the community often abuse children with a disability. Giving birth to a child with a disability is a source of shame for families and can be a reason for divorce. The Amharic word for deafness means literally '*he who cannot understand*'; while the word for blindness means '*one who is disorganised and not bright*'.[6] Adults and children with physical impairments are referred to by words that mean '*highly disfigured or mutilated*', and children with learning disabilities are called those '*possessed by evil spirits*' (Teferra 2005).

VIOLENCE AGAINST ETHIOPIAN CHILDREN WITH A DISABILITY AND THE INTERVENTIONS OF ETHIOPIAN COMMUNITY BASED REHABILITATION PROGRAMMES

A recent study of four cases of sexual abuse of girls with a disability in Addis Ababa demonstrated how the community did not recognise or acknowledge that these girls could be targets for abuse before, during or after the assault (Mohasen, 2006). In other words, they were not treated as other girls in the community would have been; girls with disability are not seen as people, and are treated as asexual:

"The more affected ones are the disabled persons. When we think about HIV/ Aids we will not have it, they think, because no one will want to sleep with us. And also that we have no feelings for men and so the rape case happens more often to us" (C6 Child interview).

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[6]   Amharic is the largest spoken official language in Ethiopia

Such children rarely receive sex education or advice or guidance. In one of the cases examined by Mohasen (2006), a young girl with learning disabilities was raped several times but did not understand that what happened to her was unacceptable. After the assault, the perpetrators were defended, both by the community and by the justice system. In all four cases, the girls had to rely on personal coping strategies to deal with the trauma of the sexual abuse, and received no official help (Mohasen 2006). However, it is not possible to understand sexual violence against girls with a disability in Ethiopia without understanding the position of Ethiopian women in society and the issues of gender inequality in the country. Women with a disability therefore, face double discrimination because of their gender and their impairment (Mohasen 2006). Many of the stories from families interviewed here are stories of rape, but there are also stories of physical violence in schools and at home, of children being abandoned and of children being punished in an excessive way, such as being locked in a house alone for hours or even days. Even if a disabled child is fostered with a new family, things can remain precarious. One boy interviewed, abandoned by his parents because he had leprosy, lives with a foster family which is supported by a project for street children:

"If I quarrel with [my stepmother], they will not let me stay in the house, then I will not know what to do…
Interviewer: Is it different for you than for the other children?

" If she quarrels with her child it does not matter, but I am not her child so it is different for me.

Interviewer: Does it happen that you quarrel with her?

C12: No, never.

Interviewer: Are you never upset or angry?

C12: I am sometimes angry.

> Interviewer: What do you do when that happens?
>
> C12: I am just quiet
>
> Interviewer: To not upset anybody?
>
> C12: Even if I am angry I prefer to be silent because she might tell me I need to find another woman to take care of me."

Yet, when discussing solutions to violence and ways to protect children from violence, solutions are always found outside of the child, never in increasing the capacity or assertiveness of the child. Among the solutions mentioned were to raise awareness within the community, including parents and other family members; make punishments for discrimination and abuse more severe and making the legal system more accessible; also to work with the police to ensure prosecutions, and to ensure they maintain confidentiality of all those involved in cases. But it was also noted that while parents should be more observant regarding their children, it would be useful to talk to the perpetrators and ascertain why they rape. Finally, many people said they would trust in God to help.

In reality, when children have faced violence, most help offered is of a practical nature such as informing the police (though in most cases this is unlikely to actually happen); assistance or advice to attend the hospital when needed; and actually removing the child from the parents to someone else's house (maybe another member of the family or a trusted friend). In this study, there was only one case noted where a child got any kind of psychological help for the abuse they had experienced. They were fortunate enough to attend the only pilot programme on sexual violence against children with a disability, in the whole country. Another mother took her child to a traditional form of psychological healing, which involved taking the child to the church and receiving holy water from the priest who asks God to heal the child.

Belief in God and the role of religion are a large part of the lives of many Ethiopians. However, this has also led to assumptions such as parents believing that God is punishing them by making their child disabled; disability has to be accepted as something God has given.

> Interviewer: "What are the things you like to do? … I would like to hear.
>
> Interviewer: Is it good to hear? Do you mind being deaf?
>
> *C9: No - because God wanted me to be deaf."*

Others believe that God will reward those who take care of those in need.

> Mother of C3: **"Even if I am suffering a lot I really work, I do good things for [my child] and her child. I do this for God. I know he will treat me well. Even if I die I believe in him. I know he will look after me when I die"**

THE FAMILY SITUATION

Sometimes, parents have difficulty looking after their disabled child and make sure there is an income for the family. One single mother said:

> Mother C7: "People accuse me for her disability. They say that I locked her in for many years and this is why she is disabled. But I did not have any choice and that is why I locked her in….
>
> Interviewer: What do you mean when you say I did not have any choice?
>
> MC7: It was difficult for me to carry her and to go to work. When I was a secretary how could I carry her and also when I was a daily labourer how could I carry her? That is why…

Much of the violence against children happens within the family, as disabled children are not recognised as full members of the family. Other disabled children and youth told how they felt excluded by their families and communities:

> Interviewer: Was there any difference in the way you were treated in the house, between your other brothers and sisters?
>
> C5: I hated my childhood in our house because my family did not treat me as well as they did the other children in the house. If parents treated their disabled children as well as the other children, there would be many changes in this country.
>
> Interviewer: Can you give an example on how you were treated different by the family?
>
> C5: At my sister's wedding, my two other sisters were bridesmaids. My sister needed another bridesmaid, and she asked everywhere, but she did not consider me even though I was in the house. And they did not think about my new clothes, or what my hair looked like. When I was a kid I did not realise that I had a right to be treated like the other brothers and sisters but when I grew up realised that this was not good and that I had a right to be treated in the same way.

Other adolescents with a disability interviewed also expressed their views that their families did not see a reason to invest in them because they were considered useless.

THE COMMUNITY AND VIOLENCE

Many children and adolescents complained about treatment by those who ostensibly were meant to be assisting them. Two disabled adolescents told about their experience with medical professionals:

> C6: "People will say what kind of man is he who raped you? And there is one example: there was one lady who had a

problem with her legs who was pregnant and the doctor told her – ' if he slept with you he can sleep with a dead body also - how can he sleep with you' So these kind of things they are happening to us, we cannot say anything about this".

> C6: "There is lack of awareness everywhere - some of the people think they are aware but many they are not. For instance, I have a boyfriend and the people they are saying your brother this and your brother that but he is not my brother. And even if I tell them he is not my brother they do not believe me. And so as not to get pregnant, sometimes my boyfriend asks me to buy the pills and I say no because I am afraid to buy them, but when he forces me to, then in the clinic or in the pharmacy they look at each other and they say to each other 'for what purpose is she buying these?' So sometimes it is better to be pregnant instead of buying these things. My parents and my boyfriend they are good in handling me but within the community it is difficult".

Their community tells some mothers that it is better to give their children away since they have a disability:

> MC8: "Sometimes people are saying why are you not giving your children to the organisation? Because it is hard to raise children with mental retardation. But it is impossible to give my children away. Because if you say that it is better to help me instead of telling me to give away my children they had better help me.
>
> M: Can you imagine that other people would give away their children to an organisation?
>
> MC8: It is poverty. In my opinion it is better to help the people in the house and deal with the poverty. The parent has to handle the poverty and their children. But for those who ask me about my children they better help me."

VIOLENCE AND THE JUSTICE SYSTEM

Not only are problems faced within the community, but also in the wider social systems. One of the most difficult areas for disabled adults and children to access is the criminal justice system. Apparently, Ethiopian law does not have an evidence code, therefore judges do not take the voice of children who are mentally challenged as evidence in cases. Nor is sign language accepted as an official language in Ethiopia. This means that judges do not have to accept it as a form of communication in the court.[7] Most cases do not end up being reported to the police because of fear that the police will tell neighbors or the perpetrators about the case, resulting in more violence. Many of those who do proceed with their case, find that the police had not in fact taken up the case. However, there are some examples of cases getting to court and winning their case.

THE SOUND OF SILENCE

Perhaps understandably, many of the adults and children interviewed are reluctant to answer questions, so there are a lot of silences in the interviews. The topic is not comfortable for many people, and raises a lot of questions and challenges assumptions. It is also clear that many disabled children and adults have imbued others' perceptions, stereotypes and beliefs about them.

Looking at the draft CBR guidelines (chapter 13) there is little mention of violence against children with a disability. There are no tools for CBR workers to work with children who face violence in their lives. It might be time to start working in the field of child protection within CBR programmes and to no longer leave the

children with a disability, their families and a good willing CBR worker to fight the violence that these children face.

CBR AS A STRATEGY TO ENHANCE *UBUNTU* FOR FAMILIES OF CHILDREN WITH SEVERE DISABILITIES IN SOUTH AFRICA

In an entirely different context in South Africa, a CBR approach has facilitated community based assistance for families of children with severe disabilities, faced with additional crises. Across South African languages and cultures, there is a traditional proverb that emphasises: *"A person is a person because of other people"* or, *"No person is an island".*[8] The significance is in recognising that no one is anyone without others; we need to recognise and help one another. These age-old traditional values of togetherness - *Ubuntu* – have been re-emphasised by the South African government and many other agencies and institutions, since the birth of the current democracy in 1994.

This resonates strongly with a systems theory framework which underpins for example, the field of early childhood development and intervention. It is widely recognised that any intervention with children with disabilities needs to be based upon a systems theory framework. This means that children need to be considered, assessed and 'managed' in the context of the dynamic relationships with and between their environments (Garbarino and Ganzel, 2000; Hartley, Murira, Mwangoma & Carter, 2005). A child needs to be seen in the context of her primary caregiver(s), her family (whether functional or otherwise), her community, and her country.

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[7]   Information gathered through Ethiopian lawyers and the experiences from the children in the court.

[8]   Which can be translated as '*Umntu ngumtu ngabantu'* in isiXhosa language, and '*Motho ke motho ka batho*' in Setswana. Both languages are widely spoken in Southern Africa.

FAMILIES IN CRISIS

A brief look at some statistics and conditions in South Africa gives an indication of the contributing factors to the number of 'families in crisis' within the country. In a total population of 47.9 million, the South African Child Gauge (Monson, Hall, Smith, & Shung-King, 2006) and Statistics South Africa (2007) indicate the following:

- Unemployment rate: at least 25.5 %.

- Divorce rate: 1-in-5.

- HIV/AIDS rates: approximately 11% (5.3 million).

- Life expectancy at birth:

    o   49 years for males.

    o   52 years for females.

In addition to these, levels of alcoholism and drug abuse, domestic crime rates and mental health problems are all inestimably underreported. These issues are combined with large areas with remote or inaccessible services.   What impact does this have on families in South Africa – especially families with children with severe disabilities? And within this context, what are some of the impacts and opportunities for CBR in this context?

A community based rehabilitation approach aims to make rehabilitation accessible to all who need it. It is an approach to service delivery, not a service in itself. It promotes equalisation of opportunities for disabled people; it promotes inclusive communities, social integration/participation of disabled people; it embodies the principles of dignity, respect for ALL people and it addresses social injustices (DPSA, 2005; ILO, UNESCO, WHO Joint Position Paper, 2004; RSA's National Rehabilitation Policy; 2000).

In order to explore some of these issues, a study was undertaken using a Participatory Learning and Action (PLA) approach (Chambers, 2007), in poor peri-urban isiXhosa, Setswana, and Sesotho-speaking communities, in the Western Cape area of South Africa. The study specifically focused on mothers of children with cerebral palsy and the systems they affect, and are affected by. Data were collected and analysed using a three-step Freirian approach (Freire, 1970; Hartley et al, 2005; Hope & Timmel, 1995,1999).

TABLE 1

		KEY QUESTION
1	Naming Phase	What do YOU think is the problem?
2	Reflection Phase	Why do YOU think this is a problem?
3	Action Phase	How can WE change this?

The mothers themselves not only identified problems and how they affected the mothers/families, but also the possible *solutions* to them. For example, in firstly highlighting the unemployment rate (25.5% of work-age population), the mothers felt that this was a no-win situation for many mothers of children with disabilities, as many cannot go out to work because their children are refused day care placements. Their response to this problem was to initiate child care services within their own homes for each other. Some of these have grown to fully registered, integrated crèches and day care centres, creating employment for some mothers, and allowing others the opportunity to seek work.

A second issue highlighted by the mothers, was the breakdown of traditional family values and the dissolution of extended families. This has led to an increase in the number of single-parent households (though these can be a 'mixed blessing', as many are actually more stable). It was noted that many of the families had broken up as a

result of having a disabled child. This was especially the case when fathers (and their families) rejected the child and blamed the mother, which is often related to traditional beliefs about the mother's role in causing childhood disability. The mothers felt that one way to resolve this was through community peer support - to get those fathers who *are* accepting their children with disabilities, to support and inform other fathers.

Thirdly, in response to the issue of HIV/AIDS, mothers identified a number of key factors: the much reduced life expectancy of caregivers and the vicious cycles of HIV/AIDS and poverty. Their response to this was to assist with provision of grass-roots information, de-stigmatisation, and to lobby for and volunteer integrated home based care. This challenges the issue of *separate* home-based care workers (e.g., some for disability, others for HIV/AIDS etc) which in turn perseverates stigmatisation.

A fourth cause of family crisis is related to substance abuse. Alcoholism is rife in the region: - the Western Cape has the highest rates of Foetal Alcohol Syndrome (FAS) in the world (**May, Brooke, Gossage, Croxford, Adnams, Jones, Robinson and Viljoen, 2000).** Drug addiction levels are correspondingly high, and new drugs (e.g., TIK) are destroying families and communities at previously unknown rates. The mothers felt they had a role in neighbourhood support and accountability and in community youth programmes.

Fifthly, in addition to the prevalence of general violent crime, the area also has very high rates of domestic crimes against women and children, markedly increasing incidents of gender-based violence especially against young girls with disabilities. The mothers felt that it was their responsibility to assist with promotion of human rights, dignity and inclusive communities through information and advocacy.

A sixth contributor to family crises is the very high incidence of depression and other mental health problems among mothers of children with disabilities. Factors contributing to this included anxiety, exclusion, guilt and loneliness. The mothers set up community based support groups; for example, the *iQhayiya* (*"self-worth")* group where mothers learn crafts etc., and produce items that they can sell but also, and perhaps more importantly, which boost self-esteem and confidence.

Finally, South Africa's history of inequality in infrastructure development has resulted in the poorest living furthest away from rehabilitation services etc. This study was situated within a combined CBR-outreach service for children with cerebral palsy. This is a collaborative effort between the Western Cape Cerebral Palsy Association (WCCPA) who provide outreach therapy services; a volunteer funding agency (*The Lions)*; the local police team (who supplied the site and some transport and financial assistance); and the parents. Originally initiated by the WCCPA, this combination of outreach clinic and community response has become an example of community ownership of services and the mothers (parents) play a driving role in decision making and problem-solving. Special mention needs to be made of the *waiting* time at the outreach service when the mothers meet, encourage each other and discuss issues of individual and group accountability: in other words, a support group in the truest sense of the term.

In wrapping up, let us return to the concept of *Ubuntu,* with its sought-after community values of openness, acceptance, togetherness and helpfulness. In the new democratic South Africa, these have not been automatically apparent and many voices have asked, "*Where is Ubuntu?*" Not hearing such responses, many have concluded that *Ubuntu* is in fact dead. However, the few preliminary findings from this study in the Western Cape Province suggest that as an approach, CBR may well be instrumental in enhancing *Ubuntu*

for families of children with severe disabilities. Considering the mothers' responses to the crises threatening their families, one can venture to conclude that *Ubuntu* is indeed alive and well in South Africa!

CONCLUSIONS

These brief examples here have demonstrated that CBR can be a successful approach in responding to families in crisis, by working within the context of the whole community - issues of social exclusion are relevant to everyone in the community, and the programme benefits all of the community members, including parents, schools, siblings and other children within community.

A CBR approach facilitates this: as the example of the mothers in Western Cape has demonstrated, a community can be created out of like-minded individuals, who can be architects of their own circumstances. The mothers shifted the emphasis on them from vulnerable women in need, to active participants in decisions concerning their own and their children's futures, which encompassed other vulnerable and at-risk members of the wider community. Though it is too early to assess the outcome of interventions in Ethiopia, the process of highlighting violence against disabled children to local CBR workers, may also prompt a similar outcome.

In line with the final Resolutions from the CBR/CAN conference 2007, we have highlighted a number of factors that are essential for successful implementation of a CBR approach to families in crisis.

Participation: DPOs and people with disabilities should participate in the development, implementation, and use of policies and guidelines.

Crisis may be of slow or sudden onset, and as noted in the beginning

of this chapter, it is always better to be as prepared as possible in order to be as resilient as possible to potential shocks. As the example of the mothers in the Western Cape illustrates, given the right tools and support, families and communities can identify actual and potential threats and crises, and ways they themselves can increase their resilience and capacity to cope with these.

It is also important that leaders of communities, governments, international organisations and agencies etc., are prepared for disasters and crisis, and that a disability-inclusive perspective is adopted in all policies and guidelines related to crisis. This process must include disabled people, their representatives and organisations as well as parents and other community members. While it is vital that CBR programmes reflect community driven ideals, it is even more vital that communities engage with and support CBR programmes, otherwise there will be limited sustainability.

Mainstreaming: CBR and other disability programmes should embrace the inclusive development approach and actively connect with other programmes that might be relevant for people with disabilities.

As the example from Ethiopia demonstrates, mainstreaming a disability perspective into programmes would enable a much broader reach than is currently happening. If mainstream child-rights organisations and programmes did this, some of the issues highlighted by the children interviewed would arguably perhaps have been prevented or resolved.

Capacity building: To ensure effective implementation of the CBR strategy there is a pressing and continuous need to build capacity of people with disabilities and service providers.

This is particularly so in the planning and preparation of responses to disasters and crises, where the inclusion of disabled people -

aside from as a 'vulnerable group' - has been weak. Agencies, responders and others involved in all aspects of crisis management need to be aware of the potential of people with disabilities to be involved in all levels of planning, preparation and response. This includes being involved as trainers and as economically productive members of their communities.

Learning from others: To enhance the development of CBR we should take lessons from other development programmes (e.g., gender, small business schemes, HIV/AIDS programmes): take their strong points and avoid their failures.

There are a growing number of examples of successful community-led responses to disasters and crisis management: the disability movement, with support from service providers and other agencies for and of disabled people must learn from these, align with them, and work to promote active inclusion of all disabled people.

Building alliances: Building alliances and networks at all levels is a key element in the CBR strategy. It is stressed that creating networks at local level is most essential to the success of any CBR programme.

In the current global climate, the likelihood of future shocks and crises at both personal and political level, is apparently ever increasing. The disability movement MUST continue to strengthen its links and engage with other civil society movements in order to increase its voice, visibility and participation. Such alliances will be mutually beneficial as there is strength in numbers, and if the disability movement does not engage with wider issues, it will be left out of community activism.

Research: In order to add to the evidence base of CBR, ethically robust research studies should be set up within and alongside CBR programmes to describe good practices,

identify indicators, and develop instruments to assess the quality of CBR programmes

Research is vital to develop a greater understanding of the effectiveness of CBR as an approach and to understand how community driven activities are accepted and understood by members of those communities. It is therefore vital to include disabled people in the research process, making them as participatory as possible, and ensuring that everyone, such as parents of disabled children and those with mental health problems and learning difficulties are included, and their needs reflected. It is essential to build capacity of disabled people engaged in research: as the example from the Western Cape demonstrates, given the right tools and support, families in crisis contexts can work with researchers to develop solutions to the problems most prevalent in their communities. This is linked to wider issues such as access to education, especially higher education, particularly for disabled women and children.

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CHAPTER 8

The changing role of CBR in disasters and reconstruction

Alice Baingana Nganwa and Anne Hertzberg

SUMMARY

The focus of this chapter is on the changing role of Community Based Rehabilitation (CBR) programmes in humanitarian emergency situations. In a disaster/emergency situation, the main challenge for a CBR programme is to facilitate and support basic humanitarian aid, service delivery and social protection for people with disabilities. However, during rehabilitation/ reconstruction and development, CBR seeks to link persons with disabilities to new initiatives and assist in raising their voices, so that their issues come on the development agenda early enough for meaningful inclusion. CBR's role is important in both these situations, but it also faces quite different challenges, and will need to function in relation to the national context. CBR has an important role to play in all the situations from emergency to reconstruction, because such programmes should always be developed near to where people with disabilities live, in order to be sensitive to their situation and needs. The chapter draws mainly on experiences from Uganda, Afghanistan and Palestine.

INTRODUCTION

CBR programmes seek to promote the rights of people with disabilities and so gain equal access to all mainstream services. As is known by those with experience in CBR, these programmes will have to be organised and implemented in quite different ways according to local resources. Some programmes have support from

government and other resources; however, they are all affected by the prevailing political situation and by threats from natural disasters. This chapter will focus on the changing role of CBR in the disaster and reconstruction phases.

In this paper, disasters refer to natural catastrophes, for example earth quakes, flooding; or manmade tragedies, such as civil wars or other situations of a life threatening nature. The disasters referred to are humanitarian and affect whole communities as opposed to a small neighbourhood. By reconstruction we mean the situation after a disaster, when the aim is to rebuild a society with infrastructure, local development and services for the population, as well as support a credible (sometimes new) national government.

In a disaster/emergency situation, the main challenge for a CBR programme is to facilitate and support basic humanitarian aid, service delivery and social protection for people with disabilities. In man made disasters (war or civil war or terrorist attacks) the government is considerably weakened and usually cannot meet its responsibilities adequately. It usually loses credibility and is not viewed as legal by a large part of the population. As a consequence basic services are most frequently financed, organised and implemented by non-governmental and international humanitarian organisations. These organisations strive to be neutral to political groupings. CBR programmes are developed by these humanitarian organisations to support service delivery to people with disabilities (Coleridge and Dube 2006). In this situation CBR has a tendency to be developed as a "top down" approach. In natural disasters the government as duty bearer may have credibility, but not the capacity, to cope with the overwhelming challenges. Usually it will appeal for similar international support.

Humanitarian disaster, whether man-made or natural, increases exponentially the vulnerability of existing vulnerable groups, as compared to other members of society. Among the most affected

are women and children, especially the girl child, older persons and persons with disabilities.

In post conflict and reconstruction situations the main challenge for CBR is to sensitise all the stakeholders involved about the challenges faced by disabled people and their families and how they can facilitate support for this vulnerable group. As a consequence, CBR should develop into more of an advocacy programme, supporting access and inclusion for people with disabilities within general development in all sectors. CBR can promote the development of specific services for people with disabilities, but hand over the service delivery to mainstream programmes, while making sure inclusion and the needed specific support are addressed. Another important area is support to DPOs. In this situation CBR should be developed much more as a true "bottom up" approach, with support from all kinds of local civil society groups and local decision making bodies. CBR should make sure that people with disabilities are represented and can profit where local development is implemented.

For the individual person with disability and her/his family, the change during a reconstruction period is not easy. One person returning to Afghanistan from a well integrated quarter for refugees in the outskirts of a large city in Pakistan said: "*In the camp life was easy, the basic services were coming to you, the children had schools, we could have health services and we could go out of the camp for small business. Coming home means we have to start from scratch again*".

In Eritrea after the liberation war people were reluctant to return, because there were no schools or health services in their home villages.

WHY IS CBR IMPORTANT IN DISASTERS AND POST CONFLICT SITUATIONS?

In Sub-Saharan Africa, disasters and post conflict situations are common and tend to be chronic. East Asian countries like Bangladesh regularly have flooding, and in countries like Afghanistan, political conflicts still have an impact on daily life. Such situations may cause impairments for people who are already vulnerable. Health services deteriorate and the nutrition situation may go from bad to worse. For example, physical injuries caused by landmine blasts, bombs, armed fights and physical violence; and the additional psychosocial consequences such as post traumatic emotional problems, anxiety, depression, grief and other mental health problems are higher in Northern Uganda than the rest of the country as a result of the 20 year conflict. Thirty six percent of the patients treated by at Gulu Orthopaedic Workshop in Northern Uganda since 1999 were disabled by a war related incident such as gunshot, burning, grenade or shells explosions, landmine/UXO explosions and mutilations (Rossini 2006). Persons with disabilities risk acquiring new impairments as happened to Mahassine in Chad.

Mahassine was born blind. She did not go to school like her brothers and sisters but stayed at home helping her mother with household chores. One day her home was attacked by rebels. Her mother, brothers and sisters were shot dead and she was shot in the leg. All she heard was frightened crying and gunshots and she could not feel her leg. Mahassine was taken to the capital N'djamena where her leg was amputated. She was then referred to the ICRC orthopaedic workshop where she received an artificial limb. Her training in using the limb was particularly challenging because of her being blind until her trainer learnt that Mahassine had to touch everything as her sight was in her hands. Adapted from http://www.icrc.org/

People who have limited mobility will not be able to flee in times of danger, those with sensory impairment will not see or hear any threats. The conditions of persons dependent on medication, for example anti epileptic medicines, will deteriorate because health facilities and pharmacies are destroyed.

The pre-disaster situation for natural disaster is usually characterised by normal community life with the family as the centre. When people with disabilities are included in their communities, they are less likely to be forgotten in times of disaster. Social mobilisation of the community and of persons with disabilities will ensure that the leaders naturally include them in issues that affect the community. The disabled people themselves will be among the leaders putting forward the needs of the people they represent. Structures for rapid communication/mobilisation will be in place, which can be used during disasters to evacuate the whole community including persons with disabilities. During the pre-disaster phase therefore, DPOs with structures that reach the family level, are of extreme importance in case a disaster does occur. Leaving the mobilisation of people with disabilities till disaster actually strikes is leaving it too late.

STAGES OF DISASTERS

There are three major phases in disasters. The pre-disaster phase in the case of conflict often has warning signs, during which the population may need to migrate. Most of the current conflicts tend to be chronic with episodes of disasters when the warring forces engage in battle or when they attack civilians. A study by the National Union of Disabled Persons in Uganda revealed that many community members are aware of an imminent strike by rebels and flee, but the Deaf community are often not informed and those with movement disabilities including, the blind, also find it difficult to flee (NUDIPU 2004).

During Disaster

During the disaster, populations move en masse to safety, creating a humanitarian crisis. The movement is not planned and persons with disabilities are often left behind. When *transport* is provided, it is often in lorries that persons with physical disabilities cannot scramble into. The necessities of life such as *food, shelter, sanitation* are provided by humanitarian agencies which often ignore, or are not aware of, persons with disabilities among the displaced persons. Most humanitarian organisations have included persons with disabilities as a vulnerable group in their manuals of operations but during implementation, the guidelines may not be followed due to front-line workers not being aware or supervised. During the Teso Floods of 2006 in Eastern Uganda, humanitarian aid did not reach persons with disabilities because it was delivered through community leaders who did not consider their difficulties in getting the information about distribution points or queuing. Sanitation facilities in camps often do not consider the needs of persons with disabilities. They are not accessible in design, they are far from the houses where persons with disabilities live and they are dirty. The loss or lack of assistive devices often forces persons with disabilities to crawl into toilets; but as a blind man confessed, he waits till night and eases himself outside his hut. He fears he may face ridicule but has no choice (NUDIPU 2004). During conflict, persons with disabilities are often left behind when family members flee. In the Acholi conflict in Uganda, some deaf people who were left behind when other members of the community fled, were captured by rebels and tortured because they could not communicate.

During chronic conflict, able-bodied persons often find a trade or go to nearby fields to dig in order to earn a living. Persons with disability who earned an income before the disaster may lose their source of income and are reduced to begging.

The loss of family members through death and separation means loss of *familiar guides and assistance*. In addition, when families flee disaster areas to live with relatives, many host families do not receive persons with disabilities readily, as they perceive them to be a burden. In some instances the persons with disabilities are abandoned by their families. A mother of four children in Gulu was hit by a land mine. She was abandoned by her family in hospital after losing her leg. Part of her social rehabilitation was tracing the family and counselling them to take her back.

CBR during the early phase of the disaster will ensure persons with disabilities are counted. When counted, they will be able to receive relief packages, accommodation, subsequent evacuations and transportation. Frontline relief workers will have them on the list of vulnerable or extremely vulnerable persons who require close monitoring. For example persons with disabilities who are separated from their family, need to be allocated a foster caretaker who could be exempted from the long queues. Sensitised relief workers will take into consideration the special access needs of PWDs.

In situations of long-standing low intensity conflict, CBR has space to grow from top-down but with a lot of community dialogue, bringing in needs and approaches from the disabled people themselves. Besides relief, medical, social, educational and access interventions can be incorporated. The persons with disabilities and parents of children with disabilities can identify where the latrines and bathrooms for disabled people should be, the type of design; access to water sources, food distribution and evacuation plans in case of an attack. Through outreach programmes of the nearest large hospital, assessment, transfer to the hospital for intensive or surgical rehabilitation, and reintegration can be carried out. Identification and follow-up should take place in the community.

In 2004, AVSI an Italian NGO and the Ministry of Health Uganda, initiated a CBR programme in 4 districts of war affected Northern Uganda. Medical rehabilitation was the focus of the project with CBR making links with social protection and educational organisations. CBR workers were trained in identification, follow-up and community mobilisation and education. Through outreach from the regional referral hospital, PWDs were identified and received rehabilitation at the hospital. Developmental disabilities were a major focus of the project. Epilepsy was found to be a significant concern, so health workers within the health units in the displaced people's camps, were trained in management and treatment of epilepsy. Landmine education was carried out and this increased four-fold the reporting of unexploded land mines.

The CBR programme however, did not address the most important concerns of persons with disabilities in the displaced people's camps. The NUDIPU study already cited above found that the major needs, in order of preference, for persons with disabilities were; poverty, lack of food, poor access to services, violation of human rights and lack of access to water. Through separate projects by different organisations, these services were provided to the community but with limited consideration for persons with disabilities.

In the 18 year-Acholi conflict already described, schools moved with displaced communities to camps. Four to six schools were in the same compound but in separate non-permanent buildings. For children with mild disabilities, displacement meant better access to education, as schools were very close to homes, education free and supported by several International organisations.

Post Disaster

In post disaster and reconstruction situations the main challenge for CBR is to sensitise the stakeholders. This will include the legal and often more credible government as well as civil society, International and local NGOs and UN agencies. As a consequence CBR should develop into more of an advocacy programme, supporting access and inclusion for people with disabilities within general development in all sectors (South Asian Network 2005).

In addition to advocacy, CBR needs to promote the development of services specific to people with disabilities. Such services could include identification and follow-up for provision of assistive devices, rehabilitative surgery and special/inclusive education. These special services should eventually be handed over to Government institutions and included in the mainstream programmes. In order to enable mainstreaming, the external organisations should work within or with the remnants of Government structures. For example if a Government had community structures that are still functional during displacement or upon returning home, these very structures could be used by the INGOs to implement CBR. The lead organisation in CBR - whether NGO, DPO or Government - should support the process of inclusion with technical and financial inputs.

A very important factor during this phase is the re-establishment of dignified livelihoods. The community which has been used to humanitarian aid is sensitised on taking control of individual and family destiny. This is even more critical for PWDs who need to be included in livelihood projects of their choice, and their skills developed to manage the projects.

In chronic low intensity conflict, the three phases of disaster tend to overlap. Thus humanitarian aid may be delivered concurrently with rehabilitation and development. During reconstruction and rehabilitation, the concerns of persons with disabilities are often not taken into consideration. The main reason for this is the weak

advocacy voice of disabled persons, not so much at community level but at policy and programme design in Government and civil society. An example is the Peace, Recovery and Development Plan (PRDP) for socioeconomic equalisation of Northern Uganda, where persons with disabilities are patch-worked in increasing household income and provision of health services, but were not made an integral part of this billion dollar plan that covers 30 districts.

In order to increase participation of persons with disabilities at this phase, it is critical for CBR to give support to DPOs so that their voices are raised. In this regard, CBR should be developed much more as a true "bottom up" approach, with support from all kinds of local civil society groups and local decision making bodies, ensuring that people with disabilities are represented and can benefit from developmental initiatives. The post disaster situations could be used as opportunities for true inclusion of marginalised and vulnerable groups. This has to start at programme design, which is often not a bottom up approach, but can start at district level or even higher up. Even when planning is bottom up, the voices of disabled people must be sought purposefully, otherwise it is easy for them to be left out.

Reconstruction and Development

When the planning and implementation of reconstruction projects start, the challenges are overwhelming. The entire population, or large proportions of it, may lack basic services such as education, health services, jobs and shelter. There are so many vulnerable groups in need of support. In the first stages of reconstruction and recovery there may be quite a good funding situation, with donors motivated for civil development. At the same time, national capacity for planning and development of services, civil society and democracy are very scarce. Key persons from the earlier regime are sacked or flee from the country; only lower officials with limited competence are left. Key persons from the earlier opposition, who

might have capacity to lead reconstruction in many sectors, have often fled the country years ago and settled abroad and are reluctant to return, or they were killed by the earlier regime. The same goes for key professional people. In this situation donor support tends to be uncoordinated and guided by the different donor's own policies, which may be contradictory and not based on assumptions about what is needed, nor upon concrete feasibility studies or needs analyses. National guidelines and strategies, for example on physical rehabilitation are not developed at this stage. There are no national disability policies or legislation. For example in Afghanistan a National Disability Law is drafted and presented for the Parliament, but is not yet approved.

This situation also affects people with disabilities. With so many vulnerable groups and lack of capacity to provide support at most levels, experiences from most countries show clearly that persons with disabilities are not given priority and become almost invisible. However, there are clear differences between the different groups of persons with disabilities. In most post-war countries the war veterans are usually visible, in particular those with movement or seeing impairments. They are given a kind of hero and/or martyr status. This may be the only group that has a small pension, for example in Afghanistan. They create their own veteran organisations, but frequently these are not well organised, and have a common basis of frustration and aggression which may lead to violent demonstrations. On the other hand, war veterans with disabling mental trauma are not visible and almost hidden.

However, persons who are disabled due to communicable disease, lack of mother and child care or congenital conditions are still the largest group of people with disabilities in a post-war country. They are the least visible group in all aspects, with no organisations to represent them, and frequently end up at the bottom of all priorities for development. They have the least access to development in most sectors.

INCLUSION OF PEOPLE WITH DISABILITIES IN RECOVERY AND RECONSTRUCTION

The overall challenge for CBR in this phase is how to include people with disabilities in recovery and reconstruction, or how to secure their access to development to the same extent as other groups in need. This can be illustrated through the following points, which show more concrete challenges and indicate some solutions for CBR approaches.

CHANGE IN KEY OBJECTIVES AND CONTENTS OF CBR PROGRAMMES: FROM SERVICE DELIVERY TO SOCIAL MOBILISATION

As mentioned in the introduction, CBR programmes have a tendency to be service oriented in the emergency phase. An example is the largest CBR programme in Afghanistan, implemented by an international NGO, with good donor support. The programme has 5 main components:

- Physical rehabilitation with physiotherapy and orthopaedic workshops

- Special education with training of groups of seeing, hearing and learning impaired children in small community centres in villages and provincial cities

- Employment support with skills training, apprenticeships, and revolving loans as support to set up of own business or other income generating activities

- Community mobilisation with CBR committees, promotion of representation in local decision making bodies, and awareness raising campaigns in communities and districts regarding the rights and needs of people with disabilities

- Facilitation of self help groups for women and men with disabilities, support to DPOs in districts and provinces (SCA, 2006)

This is a very comprehensive CBR programme, with well experienced staff who have worked with the programme for many years. These include professional physiotherapists and orthopaedic technicians, senior community workers who are responsible for group training of children, support to families by home visits, and community mobilisation. The community workers are the nearest to social workers in a country where no such education exists, and also the nearest to special education teachers where there is no formal training in this area.

In the present reconstruction phase, primary health care and schools are set up as never before in the surrounding communities of the CBR programme. Large community development programmes are set up to develop local democracy in the form of local representative bodies. The community programmes also have some resources for local construction which will benefit the village or community, such as construction of bridges, water pumps, roads, community based schools etc.

A main challenge for the CBR programme is to promote access and participation in all aspects of the general local development, access to community schools for children with disabilities, access to health services, livelihood etc. (UNMACA 2007). Social mobilisation and support to DPO development are still the weakest components of the programme. The activities in the programme are "community located": good quality services delivered from outside and started in a time of emergency. They are not defined and developed by joint actions in the community itself, according to local needs (the criteria for a truly "community based" programme). The programme has delivered its services in the same districts for many years and apparently created a kind of dependency from the community. The

good services are just continuing to be received by the population, and they do not have to fight for it, while neighbouring districts have remained un-mobilised and without services.

RECOVERY OF LEGAL LOCAL GOVERNMENT: PROMOTE EXPLICIT REPRESENTATION OF PEOPLE WITH DISABILITIES AT ALL LEVELS

In the time of emergency the CBR programmes tend to have few representatives in what remains of local decision making bodies, with no horizontal integration. Separate CBR committees consisting of persons who are respected and trusted by the community, are set up by CBR workers and volunteers, to inform and promote the interests of people with disabilities.

In recovery / reconstruction periods it is very important that CBR implementers look beyond their own programme limits, become well aware of surrounding development initiatives and work actively to facilitate the inclusion of disabled people in what is going on. That means to give very concrete information to people with disabilities, so that they and their families can utilise this information to demand access and participate in what is going on. For example, a family with a movement-impaired child must get to know that a new community school is planned and insist that the school buildings and play grounds are made accessible. The parents need to be elected into school committees.

When local government programmes are initiated, CBR programmes must ensure that people with disabilities are included in decision making bodies. CBR programmes should give training in local government procedures and structures. The same goes for representation at higher levels, all the way to parliament. With these challenges, CBR takes a new role, quite distant from service delivery and more in the direction of political support, but not of political parties.

STRENGTHEN DISABLED PEOPLE'S ORGANI-SATIONS

Self help groups can very well be facilitated in refugee camps, as well as local DPOs, with a mandate to represent the needs and interests of people with disabilities to camp administration. In the reconstruction period, DPOs will take on a new importance, to represent and advocate for inclusion in the new development, and for the right to give direction in the development according to disabled people's interests. DPOs should become a power that is listened to in civil society development. This is frequently far from reality, when for example a civil war has ended. On one side there are small self help groups, which may serve a very important psychosocial function for the individual members. At the other extreme, there might be groups already mentioned, who become very visible through violent actions but do not constructively promote the rights of people with disabilities.

There is much development support related to institutional cooperation between DPOs in post conflict and other developing countries, and DPOs in more developed countries. Frequently more developed DPOs try to teach DPOs in developing countries to copy their own structure and function, forgetting the huge differences in context and in history of organisation development. Support to DPO development from a CBR programme that already has local sensitivity and competence can be more effective in building appropriate and sustainable programmes.

In the reconstruction period a large challenge for CBR programmes is to promote handover of the services to mainstream sectors. This means physical rehabilitation should be included in health sector programmes (Wickford 2007); livelihood support in labour/ employment programmes; special needs/inclusive education in schools; social support and protection as well as psychosocial rehabilitation in social welfare programmes, etc.

A dilemma is that the capacity for supervision, on-the-job training and upgrading of technical expertise, may be developed within the CBR programme, but there may not be capacity to develop national training programmes and monitoring systems. For example, physiotherapy and physical rehabilitation services in Afghanistan are formally integrated in the new guidelines for primary and hospital health care, but in practice these services are mainly located at health facilities but not integrated in the health services when it comes to budget, management and monitoring. The hand over process starts at 'both ends', at one end lobbying donors and government for an increase of health budgets in order to incorporate the new services; and with CBR programmes making agreements with the health facilities to gradually hand over and integrate rehabilitation services. Supervision and monitoring will need a much longer hand over time. If the CBR programmes abruptly stop this support for quality development, the hand over of services will quite frequently result in a serious deterioration of services.

Perhaps an even larger challenge is to include children with seeing, hearing and learning disabilities into schools with no competences or teaching materials for the teaching of these children. While this is slowly built up in the CBR programmes, a sudden hand over will actually result in a violation of these children's rights to appropriate education.

In hand over periods CBR programmes will have two important roles: to promote and lobby government and donors to include services in mainstream programmes, and at the same time to try to keep up the quality of services. The CBR programmes must act both as lobbyist for public services and as a resource bank to keep up the quality of services.

CBR PROGRAMMES MUST SUPPORT POLICY DEVELOPMENT

In a reconstruction period it is also important that CBR programmes support policy development in general. Policies and guidelines in the different sectors involved can give a much needed direction to the hand over process.

What will be the aims of good CBR programmes when services are handed over successfully? It should mean that people with disabilities will have better access to services in the ordinary system, in other words, more equity of care. The CBR programmes can develop a much stronger focus on inclusion in community development, advocacy and support to DPOs. CBR will continue to lobby for and demand good services, but the programmes themselves should, in a long term perspective, not be too much involved in delivery of services that can be accessed in mainstream provision. Possibly some preparatory training of children with special needs, some community based physiotherapy with emphasis on advice to families and field workers, some support to livelihood projects should remain. But the main emphasis for CBR should be much more on community and civil society development, to mobilise society to include people with disabilities in this process, and empower people so that they are able to participate and utilise their resources actively. .

CONCLUSIONS

Regardless of the situation and context, a CBR programme may be the best tool to serve people with disabilities because such programmes should always be developed near to where people are and be sensitive to their situation and needs. In emergency situations CBR can build up basic services or make sure that such services are accessed by people with disabilities. In reconstruction periods a

flexible CBR programme can change in accordance with the change in the community, hand over services and become an important vehicle for development of DPOs, community mobilisation and participation in new development.

Disasters, whether natural or manmade, increase the vulnerability of the persons with disabilities. CBR is an important approach to ensure inclusion of persons with disabilities and it needs to evolve with the different phases of the disaster situation. The reconstruction phase is particularly important for inclusion of persons with disabilities as it is a new beginning for all.

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CHAPTER 9

Inclusive education (IE) and community based rehabilitation (CBR)

Orpa Ogot, Judy McKenzie and Servious Dube

SUMMARY

This chapter highlights the global concern for ensuring access to education for the millions of disabled children who do not attend school and who must do so if the Millennium Development Goals are to be realised. Examples from South Africa, Kenya and Sierra Leone relate to teacher training, inclusive education policy, and the role of non-governmental agencies in the implementation of inclusive education. These case studies illustrate practical experience and challenges in Africa. The South African experience shows the advantage of government policy providing direction for the implementation of inclusive education. It stresses the need for change in education systems to accommodate all learners, rather than labelling a group of children according to their impairment group. The case studies from Kenya and Sierra Leone show the importance of capacity building for teachers and other community stakeholders. Finally the challenges to the implementation of inclusive education in developing countries, such as the high poverty levels, large class sizes, and traditional beliefs on disability, are also discussed. The importance for collaborative efforts among all players in Education is emphasised as the way forward towards achieving 'Education for All (EFA).

INTRODUCTION

Education is an instrument for empowering every citizen and is important for reducing poverty and enhancing livelihoods. It is equally important for children with and without body and functional impairments. But previous to the introduction of inclusive education strategies, children with impairments were generally turned away from educational establishments and either remained uneducated, were educated at home or, later on, sent to special schools. However the exclusive nature of special schools was not found to be morally acceptable and the ideology of IE emerged. Inclusive Education is defined by Door et al (1994) as providing to all students, including those with significant disabilities, equitable opportunities to receive effective educational services. The emphasis is on children with disabilities who have been traditionally excluded from mainstream education, to be supported with the needed supplemented aids and support services in age appropriate classes in their neighbourhood schools, in order to prepare students for productive lives as full members of the society.

The introduction of IE has not been without its challenges. In many cases, IE has been shown to be very beneficial in improving educational access for children with disabilities and positively affecting community attitudes to disability (Kisanji 1999). Other evidence shows that IE can result in challenges for children without disabilities and be associated with disrupted classes, poor teacher pupil ratios and discipline problems (Afako et al 2002). Different challenges result when introducing IE in income rich or income poor countries. On the one hand where special schools are well developed there are more appeals from parents wanting to keep their child at special school (Russel 2000), but where there is little special provision, the challenges are more closely related to a lack of resources, both human and financial (Jonsson and Wiman 2001).

The philosophy underpinning CBR is compatible with IE in that it

promotes and supports inclusion in all forms of society (this includes education). It strives to strengthen community inclusion for such children in any way that it can. CBR has developed concurrently with initiatives in education. These are schools that provide valid education experiences for all groups and ranges of ability within one framework. The WHO/ILO/UNESCO (1994 and 2004) joint position statement on CBR stresses implementation through the participation of persons with disabilities, families and communities in order to help facilitate an inclusive society. It cites the need for educating children with disability as a human rights issue and provides the moral and ethical defence for implementing inclusive education. Thus we begin our discussion by exploring CBR and inclusive education and the links between them.

BACKGROUND TO INCLUSIVE EDUCATION

While there are many definitions and different understandings of inclusive education the fundamental point is that every child has a right to belong. Kunc (1992) expresses this in a powerful way:

"*The fundamental principle of inclusive education is the **valuing of diversity** within the human community. Every person has a contribution to offer the world. . . . . When inclusive education is fully embraced, **we abandon the idea that children have to become 'normal' in order to contribute to the world. Instead we search for and nourish the gifts that are inherent in all people**. We begin to look beyond typical ways of becoming valued members of the community, and in doing so, begin to realise the achievable goals of providing all children with an authentic sense of belonging*" (1992;p38-39)

This definition stresses the important idea of diversity. Everybody is different and the difference should be seen as a resource, rather than as a problem, because every person has a different contribution to make to the world.

Tilstone (1998) refers to inclusion as the opportunity for persons with disability to fully participate in all of the educational, employment, consumer, recreational, community and domestic activities that typify everyday life. This definition encompasses whole life inclusion rather than the emphasis on schooling. The opportunity to participate implies active involvement and the ability to make choices as opposed to the passive receipt of a pattern or condition that has been made available. Basing the arguments on the idea that inclusion represents the opportunity to participate, requires changes in professional thinking and practice (Tilstone, 1998).

Daniels (2000) in reference to the Salamanca 'Framework of Action' (UNESCO 1994) stresses the fact that the fundamental principle of the inclusive school is that all children should learn together, whenever possible, regardless of any difficulties or differences they may have.

According to a report commissioned by World Vision, it is estimated that one third of the 77 million children still out of school are disabled children (UNESCO, 2006). WHO (2004) states that about 10% of disabled children are in school, in Africa. Thus globally, ensuring the inclusion of disabled children is critical to achieving the goal of universal primary completion (UPC) by 2015 (World Vision, 2007). This state of affairs is a particularly central concern for international development cooperation if social inclusion is to be achieved. The development of the WHO (2008) Community Based Rehabilitation (CBR) guidelines currently in the process for publication is viewed as a strategic opportunity in promoting Education for All (EFA) initiatives.

Most disabled children and adults are consequently denied participation in all areas of development due to lack of education. Education and inclusive community development approaches are instruments for empowering every citizen and are important for

reducing poverty and enhancing livelihoods in developing countries. Charlton (2000) describes this poverty as deep-rooted degradation, dependency and powerlessness experienced by five million persons with disabilities in the world.

WHAT IS COMMUNITY BASED REHABI-LITATION (CBR)?

The concept of CBR as defined by the WHO, ILO, UNESCO joint position statement:

"… a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services" (2004).

The key to this definition and understanding of rehabilitation is that it places rehabilitation firmly within a development context and recognises the complexity of factors that impact on disabled people within a universal model of disability. The concept of the 'equalisation of opportunities' in CBR can safely be said to have its roots in education, whether this is education that enhances the independence of the intellectually disabled child or allows a deaf child to matriculate from school and attain a university education. To realise this, social inclusion should begin in childhood where all children learn together. The complexity of CBR is illustrated in the WHO matrix (2004, Chapter 13).

It is clear that education is an important part of the CBR strategy and interwoven with the other four CBR components such as health, livelihood, social and empowerment. The concern within CBR regarding the social inclusion of disabled people forms a logical link to inclusive education and it is this link that is explored below.

While the matrix does not specifically state inclusion as an area of action, it is implicit in all areas of operation. However, it is evident that there are debates about what education and inclusion mean to different people in the human arena. This is discussed later.

EDUCATION: A HUMAN RIGHTS ISSUE

Access to quality basic education is a fundamental human right, reflected in a number of international instruments, including the 2006 UN Convention on the Rights of Persons with Disabilities. This Convention reiterates the right of disabled people to inclusive education, and it will play a key role in the implementation of this right once it has entered into force (World Vision UK, 2007). The fact that many countries have signed this Convention gives hope and so efforts have to be made to increase the number of countries ratifying it to justify its implementation.

The strategy to address exclusion from education is widely agreed to be that of inclusive education, and this is articulated in the Salamanca Statement in 1994:

"Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system" (UNESCO, 1994).

Thus a policy and theoretical link can be made from CBR to inclusive education. Before exploring the nature of these links it would be useful to examine briefly challenges to the implementation of inclusive education.

INCLUSIVE EDUCATION FOR IMPROVING EDUCATIONAL ACCESS

While the above policy instruments provide a powerful imperative to implementing inclusive education, the reality on the ground presents a number of challenges to implementation.

Reid (2005) suggests that some enabling and catalytic reinforcement needs to be in place to provide external support for inclusive schools. For example:

- The extent to which local and national policy is committed to inclusion has impact on individual schools.

- The way in which resources, in terms of funds, personnel and expertise are distributed throughout the education system can offer incentives and disincentives for schools to become inclusive.

- Influencing the national and regional policies towards inclusive education in Africa is a step to creating enabling learning environments that support the education for all children and by large targets the disabled children.

In reference to certain African countries, ILO (2004) notes that despite their having introduced disability related legislation, the laws have not yet been implemented. Strong campaigns by DPOs, civil society and NGOs are required to push governments to take action on facilitation of inclusion in mainstream education. While in other African countries, the existing national laws need to be reviewed in order to document goals and mechanisms for achieving equalisation of opportunities for persons with disabilities.

LINKS BETWEEN SPECIAL AND MAIN-STREAM SCHOOLS

Where there is current educational provision for children with impairment that is located within special educational settings this needs to be innovatively linked to mainstream provision. Tomlinsen (1982) cited in Tilstone (1998) reiterates that although society is committed to 'Education for All' certain groups of children continue to be excluded from mainstream education mainly due to fear or prejudice. Special schools, although intended to support children with disabilities (especially those with severe disabilities), are sometimes used as safety valves and social controls for the children who could be seen to be posing a challenge to mainstream schools. It is also thought that special schools encourage negative labelling of children (Tilstone 1998). The question is how special schools (where they exist) can avoid the negative labelling of children with disabilities and support an inclusive education system. Ainscow et al (2006) suggest that links formed between special and neighbouring schools could harness their relationship, thus developing mutual benefit to all children in both special and mainstream schools. The examples given by Tilstone (1998) for activities that the schools could be involved in are:

- Small groups or classes visiting other schools (special or mainstream) for shared learning activities such as music, P.E, and drama;

- Children on shared placements between mainstream and special schools;

- Special schools staff offering advice and support for children with special and teaching styles;

- Pupils using other schools' facilities such as the swimming pools; joint professional development between mainstream and special school staff.

Well functioning and resourced special schools would serve as resources to teachers within the community schools, with the provision that such schools need to be versed not only in technical skills relating to disability, but are also knowledgeable about inclusive education practice. For example they can help mainstream schools learn how to respond to the needs of all learners. Continuous teachers' capacity building is an integral part of working towards the enhancement of education for all children. It does not only concern disability related knowledge but could also entail participation in practitioner-based inquiry, which enables them to investigate, plan, monitor and evaluate their own practice and to therefore keep the track of improvements, as one crucial means of reaching all the learners (Ainscow, 1999).

There is a growing body of evidence (Engelbrecht & Green, 2006) showing that inclusive education can work in developing countries, depending on the level of government and other stakeholders' cooperation to make it a global action programme in education reforms. Currently, there are good practice examples on inclusive education that could demonstrate how the concept could work in the field as a research ground for effective inclusive development.

EXPERIENCE IN SOUTH AFRICA

Inclusive education in the South African Education system is defined in the White Paper 6 (Department of Education, 2001) as:

"Inclusive education and training

- *Are about acknowledging that all children and youth can learn and that all children and youth need support*

- *Are accepting and respecting the fact that all learners are different in some way and have different learning needs which are equally valued and an ordinary part of human experience*

- *Are about enabling education structures, systems and learning methodologies to meet the needs of all learners*

- *Acknowledge and respect differences in learners, whether due to age, gender, ethnicity, language, class, disability or HIV status*

- *Are broader than formal schooling and acknowledge that learning also occurs in the home and the community, and within formal and informal modes and structures*

- *Are about changing attitudes, behaviours, teaching methodologies, curricula and the environment to meet the needs of all learners*

- *Are about maximising the participation of all learners in the culture and the curricula of educational institutions and uncovering and minimising barriers to learning*

- *Are about empowering learners by developing their individual strengths and enabling them to participate critically in the process of learning"*

(Education White Paper 6, July 2001, pg. 16).

This definition makes it clear that the education system must be changed to accommodate all learners. In inclusive education there is recognition that barriers to learning can be located within the system and therefore the environment, our attitudes, the curriculum and teaching methods must be adapted in such a way that barriers can be minimised.

The experiences reported here are drawn from three initiatives, with the caution that these are not the final research findings:

- Pre-service teacher training at the University of Fort Hare

- Implementation of South African education policy in pilot projects on screening, identification, assessment and support and inclusive learning programmes for the Department of Education

- Support to 30 disabled children and their families in inclusive

education settings in the Buffalo City area in the Eastern Cape in a project run by REHAB.

PRE-SERVICE TEACHER TRAINING AT THE UNIVERSITY OF FORT HARE

Teachers on the four year B. Ed programme undergo two courses in inclusive education, one at second year level which serves as an introduction to inclusive education and alerts student teachers to the cross cutting nature of this approach at the beginning of their classroom practice. The fourth year course is more technical and aims to provide teachers with some of the skills that they would require in an inclusive classroom.

The younger student teachers are more positive about inclusive education and appear to grasp the need to see disability as part of the range of diversity. However, they are fearful of disability and there are many negative feelings about inclusion. Their concern is based on the fear that they will not get the support that they need. It is also because they do not see a lot of inclusion happening in classrooms as yet. They also experience a great deal of indiscriminate labelling of children as having attention deficit disorder (ADD) or being "slow learners".

The above experience of student teachers indicates that there is a potential role for CBR programmes in ensuring that schools are knowledgeable and welcoming to children with disabilities. This in turn will increase the chances of a more positive experience for student teachers in the classroom and impact on their willingness to be agents of change in implementing IE. The following links with CBR programmes could be explored:

- Creation of an awareness of disability within the mainstream education sector. The involvement of disabled people themselves will be highly effective. Teachers' unfamiliarity

with disability and groundless fears can be dealt with in a supportive way.

- Resource for support of teachers in adapting for disability in the school and classroom. Rehabilitation expertise on suitable seating arrangements, mobility devices, communication aids etc., is invaluable to the learning and teaching process.

- Correct and up to date knowledge on disability and the impact of labelling on a child as in the case of ADD

It indicates that there is a strong role for CBR practitioners, in pursuit of an inclusive society, in creating positive perceptions of disability amongst learners and teachers.

PILOT STUDIES BY THE DEPARTMENT OF EDUCATION IN SOUTH AFRICA

The Department of Education provides detailed information on the policy development process in South Africa and the research emanating from the process (Department of Education website). Within Education White Paper 6, two significant innovations are made:

1. Support is redefined from supporting individual learners with 'special needs' to addressing barriers which prevent optimal learning and teaching from taking place.

2. There is a move away from labelling according to categories of disability as an organising principle for schools and support services. This is based on the realisation that there are also other factors that create barriers to learning such as language, poverty, class, health, race, etc. The key feature in educational provision becomes the identification of levels of support, which would require adjustments to the system as a whole.

According to the *Draft National Strategy for Screening, Identification,*

Assessment and Support (Department of Education, 2006), both the above-mentioned conceptual shifts will alter current assessment procedures and the way in which support services are made available. It would also influence the roles, responsibilities and utilisation of the staff providing support and ultimately the teaching methodologies as well as the management of the schools.

The implementation of these changes, based on experience in the rural areas of the Eastern Cape, illustrate the potential for CBR programmes to support the development of Inclusive Education. We discuss below some of the identifiable gaps in the system that could be ideally addressed through CBR strategies.

Early identification: Health and CBR practitioners are likely to be the first to detect major forms of impairment that require early intervention. The extent to which the disabled child receives this enhances their possible experience of inclusive education. The CBR practitioner can make early links to the educational establishments in the community and so facilitate the child's entry into school. Early intervention may be perceived as happening before school, but it is necessary to consider that mild to moderate sensory impairments may not be detected before school. Both visual and hearing screening within the schools can be effective at this stage and further interventions can be coordinated with the department of health.

Disability awareness and advocacy: In some of the more remote districts of the Eastern Cape, special schools are becoming overcrowded as a result of the drive to get all children in school. Theoretically, many of these children should be placed in regular schools in an inclusive system. However, the special schools have noted negative attitudes in regular schools that make inclusion difficult. The overall disability awareness that CBR aims to develop within the community can help to overcome this barrier.

High support needs: Inclusive education policy in South Africa mandates several support structures for learners with high support needs. The institutional level support team, based in the school, supports the learning and teaching process to maximise inclusion of all learners within the school. The district based support team (DBST) has the role of supporting, monitoring and expanding the capacity of schools to meet a wider range of learning needs (Department of Education, 2001). While the Eastern Cape Department of Education has created a DBST in many districts, the effectiveness of the team is hampered by the lack of skilled rehabilitation personnel in the rural areas. The skills of the CBR practitioner are especially relevant where a child has high support needs resulting from disability. Their expertise in rehabilitation will provide valuable input to the DBST.

Special schools and dual roles: In South Africa some special schools perform dual roles of:

· Meeting high support needs

· Acting as a resource to surrounding schools in terms of their disability expertise

However, in the Eastern Cape this second function of the school is still underdeveloped. CBR programmes could assist in this regard by making links between the school and the community. Special schools could open their resources to CBR programmes thereby providing their specialised skills. As yet this remains a possibility to be explored in the Eastern Cape where there is limited deployment of CBR workers.

Inter-sectoral links: These are illustrated in the CBR matrix (Chapter 13). CBR is by definition, a multi-sectoral enterprise, bringing an array of resources to bear upon the social inclusion of disabled people. In this sense, CBR is a repository of disability knowledge in the community as well as a central point in networks

of and for disabled people. The important role is to link different partners who might find a need for each other's services at different times. Inclusive education policy in South Africa requires the participation of other sectors in order to maximise on resources for support within the local community. One example in the Eastern Cape was a young man who attended the local school but struggled to get there on his dilapidated crutches. What was needed was a referral to an appropriate health service and a negotiation with his parents and community as to transport to school. The school was willing and did their level best to do these things. However, as they were not familiar with the process, it took too long and the child eventually moved away to a special school.

Home-school links: There is usually some distance, physical and psychological, between the school and the home. CBR workers who are based in the community could act as a valuable link. They know the contextual factors that impact on the disabled child and can bring these to the attention of the school, and at the same time they are able to inform parents as to expectations at school.

REHABILITATION (REHAB) PROJECT

This project is being coordinated by the Association for the Rehabilitation of People with Disabilities (REHAB), a disability rights, non-governmental organisation based in East London, South Africa, with the aims of examining the practical implications of the implementation of IE for children with disabilities, as outlined in Education White Paper 6: Building an Inclusive Education and Training System (July 2001).

The REHAB project works with a small target group of young children with severe disabilities, their parents and their local schools to address the barriers preventing their full participation at school. The practical information regarding support to educators and parents, the adaptation of the curriculum to meet the specific needs of the

child and the costs involved would have value in informing future planning for the inclusion of children with disabilities, according to McKenzie (2007).

Based on the experience of this project, the following links to CBR can be noted:

Parent support and education: This is a crucial aspect of both CBR and IE. One of the difficulties experienced in the REHAB project is that parents/ caregivers have limited expectations for their children. Where they have not seen role models of successful disabled people, they tend to have a restricted view of what is possible for their own child. It has also been noted that many health professionals are not sufficiently educated about inclusion to motivate and enlighten parents about what they can expect for their child. Special schools are still often assumed to be the main educational placement for the disabled child. CBR can play a role in assisting parents to craft a vision of their child's future which reflects social inclusion at all levels. Inclusion starts in the home. This includes the recruitment of out of school youth to attend the local school.

At the same time, parents often face negative experiences as they pursue inclusive placements, from the negative attitudes by community members to school rejection by the school heads because of lack of awareness in inclusive education (McKenzie & Loebenstein, 2006). If CBR aims for an inclusive society, then support for parents in this process should be part of their role.

Assistive devices: Many children can cope well in school in spite of their disabilities with the appropriate assistive devices. While the provision of these devices could be the responsibility of the health or education authorities, the school needs support in this respect. In the REHAB project, rehabilitation personnel assess the child for assistive devices **in the classroom.** The devices that could be useful at home might be less useful in the classroom and this is

why it should be done in the learning environment. The CBR practitioner can assist by creating awareness of accessibility issues, linking the school to professionals and disabled people who can assist. They can also educate and support the teacher in the use of assistive devices.

Classroom adaptations: This refers to any adaptation that is made to the curriculum to create access to the curriculum. The term curriculum is used in the broadest sense to mean all activities that take place in the learning environment. It includes sports, school assemblies or singing as part of curriculum, same as mathematics or any other academic areas. The CBR practitioner has a role to play in educating teachers about the adaptations that need to be made for the disabled child. For example, in the REHAB project the use of black chalkboard paint that improves the colour contrast has been recommended to replace the green background in order to support children with visual impairments. The need to face the light and make use of visual cues for a child with a hearing impairment has also been highlighted.

CHALLENGES FOR INCLUSIVE EDUCATION IN SOUTH AFRICA

While these are all areas of potential collaboration there are several precautions that CBR programmes need to take into account in working with inclusive education.

a)   Learning failure is a curriculum issue within the school. Within a medical model of disability it was quite possible for doctors and therapists to prescribe an educational placement for the disabled child. In the social model the barriers to learning arise through the interaction between impairment and contextual barriers and these needs should be determined within an educational context. In the Eastern Cape, a progressive screening, identification, assessment and support

tool/process has been implemented. District staff, educators and school heads are being trained on how to determine levels of support, rather than category of impairment; and to make decisions as to how to provide this support based on a range of policy imperatives and practical realities. It is **not** the role of the rehabilitation personnel to make this decision, although their input continues to be highly valued in the process.

b)   There is a complex relationship between learning failure and disability. Over the past few years, a range of disabilities have been identified in the classroom such as learning disabilities, attention deficit/ hyperactivity disorder. It is not clear how these disabilities can or should be accommodated within CBR and this should be a cause for reflection in working within the education sector.

c)   CBR programmes need to ensure that they are able to prepare parents and disabled children for education in an inclusive education system. If there is a need to lobby for change, in the absence of suitable provision within the mainstream, then CBR practitioners should contribute their voice for change. They should work with the department of education to change the system as far as possible rather than setting up separate facilities, with the danger of moving toward segregated education again. In South Africa the numbers of children enrolling in special schools has increased since the adoption of inclusive education as a policy (Department of Education, 2006).

d)   Inclusion of children with intellectual disability in the classrooms is a challenge to many teachers who believe they cannot cope with the regular curriculum, and this perpetuates the failing of children. They need to be encouraged to proceed in little steps (task analysis) and to take into account the parents' expectations for the child. CBR programmes can

highlight the valuable roles that intellectually disabled people can play in society. This can be achieved through the development of intellectually disabled people as self-advocates and role models for changing perceptions.

In conclusion, the South African context illustrates a situation where an enabling inclusive education policy is in place. However, implementation challenges remain significant. The above discussion suggested many ways in which CBR could play a supportive role to IE, while noting that there is minimal development of these links. This suggests that it would be a boost to the implementation of IE policy if CBR were further developed in the country.

EXPERIENCE IN KENYA AND SIERRA LEONE

Leonard Cheshire Disability (LCD, 2008) has implemented two models of inclusive education programmes in Africa, one at Oriang in Rachounyo, a district in Nyanza Province in Kenya, and the other at Kabala in Konoidugu District in Sierra Leone, for over 5 years now. The examples described in this section are compiled to demonstrate that inclusive education is not just rhetoric, but can be used as a tool to transform lives of disabled children even in situations where appropriate educational provision does not exist for the majority of people.   This transformation can also address the goals of CBR for full participation of disabled people in their communities.

THE ORIANG CHESHIRE INCLUSIVE EDUCATION PROJECT

In Kenya, the LCD initiative in Inclusive Education covers five primary schools. Prior to the initiation of Oriang Cheshire Inclusive Education Project (2002 -2007) a few children with physical disabilities from neighbouring districts resided at Oriang Cheshire

Home and attended a nearby primary school. The needs of these children were unmet in this environment mainly because:

- teachers lacked the skills to support children with disabilities;

- peers were not prepared to work with children who looked different because of their special needs;

- a hostile physical environment was not adapted to suit their mobility needs;

- there was lack of adaptive aids for children with special needs;

- learning materials were generally inadequate to enhance quality education for all the children;

- there was lack of awareness on disability issues compounded, with negative cultural beliefs within this community that attributes causes of disabilities to ancestral sins and other misdeeds.

A needs assessment carried out in 1999 established that the Oriang community had several children with disabilities who were either in the schools but remained unidentified or, along with many children without disabilities, were not accessing any education. The Oriang Inclusive Education pilot project was thus initiated with an aim to increase the number of all children, disabled and non-disabled, receiving primary education. It has striven to bring about a change in culture, policy and negative practices in order to support all children to gain quality education (LCD 2002). The programme fits in the philosophy of inclusion that **advocates schools and education for all** as a prerequisite for an inclusive society. The restructuring of the schools' cultures, policies and practices has been the greatest strength of the project towards enhancing the learning environments to respond to the diversity of students within the locality of the schools.

Through the use of participatory strategies, the project's stakeholders within the Oriang community, with the support of LCD, worked to enhance the learning environments in order to support learning for all children. Establishment of committees representing groups such as parents of disabled children, persons with disabilities, community health workers, teachers and school committees have cooperatively worked to enhance environments both at the homes and in the schools. It has been in line with the social model of disability that espouses the removal of barriers by the society as means of creating level playing ground for all children (LCD 2005).

Capacity building

The teachers and community have been empowered through several training events, enhancing skills in resource mobilisation, enabling some schools with dilapidated buildings to acquire new permanent classrooms and also to access clean water for the control of hygiene within the five schools. Teachers have changed to learner-centred approaches, including incorporating child-to-child activities, enabling children's voices to be heard and also to actively participate in their learning. The situation then is captured by this quotation from the head teacher of one of the pilot schools (LCD 2003):

'This girl on a wheel chair avoided eating any food even drinking water for fear of having to visit the toilets at school that were not adapted to suit her condition. By that time we did not know that she needed a particular type of toilet. We knew there was a special toilet for the children living in the small home for the physically impaired but it did not occur to us that the same was crucial to be erected at the school. Now I realise the purpose of an adapted toilet' (Head teacher Oriang Primary, 2004).

The community health workers administer and train parents in basic physical therapy activities and primary health care initiatives. Parents and community health workers share their experiences and are able to manage different children with disabilities. The trained parents have been engaged in training other parents on the same topics so

as to create a trickle-down effect, monitored by the community health workers (LCD 2006).

Diseases Control: Epilepsy is a condition erroneously associated with demonic powers within this community. Those who suffer from it are highly discriminated against. Epilepsy has been controlled through training support given to a nurse working at the local dispensary. The nurse can now dispense the drugs, which are bought at the dispensary at subsidised prices, and at the same time counsel parents. Thirty five parents have reported reduced convulsions in their children and increase in school attendance due to reduced stigma. An early identification, stimulation and intervention strategy has proved useful in reducing the impact of disabilities on children. Hearing problems, mainly caused by ear infections and which interfere with learning due poor hearing have been reduced through the training of some teachers on ear hygiene. Children selected to be ear monitors have reported on the cases of children with *otitis media*, which is followed by mopping by the teachers. The consequent assessments revealed reduced ear infections amongst children in the five schools (LCD 2007).

Physical adaptation of the schools: Schools have striven to adapt the environment to make it more conducive for learning. This has included widening classroom doors to allow for wheelchair entry, building ramps at doorways (rather than steps), painting classroom walls in brighter colours and widening windows to improve illumination for both visually and hearing impaired children. They have also built adapted toilets to support children with physical disabilities. Some of the school trees have been turned to timber for the provision of desks and chairs and other trees planted to maintain the environmental stability. This initiative has improved the seating arrangement allowing cooperative learning where children can share and give support to each other through peer tutoring (LCD 2007).

Awareness creation: Annual Inclusive Education and child-to-child days have brought the community and other stakeholders together with each group using performing arts to create awareness on disability issues. Documented case studies have also enhanced the sharing of success stories widely (LCD 2006).

Enhanced enrolment of children with disabilities has been experienced in the schools from 225 in 2003 (2nd year of the project) to 557 out of 2700 children in 2007. As a result of the schools' improvements, the general school enrolment, and improvements have been registered.

Disability resource centre: The centre stocks school textbooks which are borrowed by the schools to supplement what they do not have in their own libraries. Video shows that highlight issues of disability and ways in which to improve disabled people's lives are also shown periodically at the centre with mobile shows taken to different schools once a month. Both teachers and pupils have worked cooperatively to produce learning materials for the resource units in schools and this has enabled the teachers to tap talents in children (LCD 2007).

Parent support groups and children play groups: These meet at the centre once a month for psychosocial support and sensory stimulation respectively. Physical therapy carried out by an occupational therapist and further implemented by parents and supported by the community health workers in the homes has improved various disabling conditions in the children.

KABALA IN SIERRA LEONE

In Sierra Leone, which suffered 11 years of armed conflict, the Kabala community based project is implemented by LCD in a rural community. The conflict destroyed communities, families, infrastructure and all the basic facilities. This pilot project,

implemented over 2 years, aimed at facilitating access for disabled children, disabled young adults and their families to basic education and sustainable livelihood in the area surrounding Kabala Township (LCD 2007).

Disability is a prominent issue in Sierra Leone and has been compounded by more than a decade of civil conflict in the country, which has left thousands of adults and children amputees and the general population traumatised. There has also been an increase in the prevalence of polio among children because of disruption of vaccination campaigns. Schools have been destroyed or looted. Access to care and services for disabled people is limited, many families are single-headed by women and poverty is endemic. Children and adults with disability in this context, represent a very vulnerable population group. Their opportunities for education, self-development and achieving self-reliance are extremely limited.

In 2003, LCD carried out a survey throughout the Kabala community to determine the status of disabled people. The finding of the survey revealed that about 7 percent of the population of Kabala Township (4000-5000) comprised people with disabilities who needed support in order to function within the community. Seventy percent of this target group were children, many of whom did not have access to basic education and health services. Lack of access to basic education was as a result of combined factors, which included abject poverty amongst disabled family circles, lack of access to basic therapy and prosthetic services, along with lack of awareness and knowledge on health and disability issues (LCD 2007).

In Kabala, LCD worked with the community to develop an appropriate and sustainable community project, which is implemented through a local Volunteer Management Committee and community development workers. The committee has a good representation of both women and men, and young people with disabilities.

Disability awareness creation: The Kabala project has managed to raise awareness on disability and demonstrated the abilities of disabled children, youth and their families through small but effective interventions. The inclusive approach adopted, combined with economic empowerment training, ensures the sustainability of the project and its ownership by the community. The rehabilitation services provided through the project have improved the quality of the lives for children and adults. At least 30 disabled children have been enrolled in mainstream primary schools in 2 years.

Environmental adaptation: Ramps and environment modification constructed in 2 primary schools in Kabala town have increased access to classrooms for wheelchair users. At least 20 primary school teachers have been trained on teaching techniques, disability awareness, and specific communication skills. Over 100 physically disabled children have been provided with orthopaedic and prosthetic appliances in Kabala in collaboration with Mercy Ships / New Steps to enhance their mobility and general functioning (LCD 2006).

Learning materials: Learning materials provided to two schools augmented the training that had been received by the teachers thereby enhancing the schools' learning environments. At least 30 families of disabled children within 15 miles radius outside Kabala have been trained in small business development and included in a revolving loan scheme to enhance their livelihoods. The leadership training for 12 members of the Volunteer Management Committee has improved the management skills of the committee (LCD 2006).

Other benefits to the schools and the community are safe drinking water from two wells with hand pumps, which were constructed in primary schools and which have contributed to reduced waterborne illnesses.

One of the key strengths of the both the Oriang and Kabala pilot projects is that they have given the opportunity for LCD to engage

with and influence policymakers and other international development organisations. LCD has the opportunity to further strengthen these linkages and increase the coverage of the project with appropriate interventions (LCD 2006).

CHALLENGES OF LINKING CBR TO INCLUSIVE EDUCATION IN AFRICA

Major barriers to implementation of linking CBR to inclusive education in developing countries include high poverty levels, belief in retrogressive customs and traditions, poor infrastructure, large class sizes, understaffing in schools, inadequate teaching skills, rigid structured school curriculum, inadequate medical support services, un-adapted physical environments and lack of government policy. Stakeholders frequently highlighted these challenges during qualitative surveys conducted by the Oriang Project in western Kenya (LCD 2006).

Weak national economies have resulted in widespread poverty. More than 50% of community members live on less than one US dollar a day in most African countries. Such parents are therefore hard-pressed to provide material support to schools, hence poor learning facilities in some schools make Inclusive Education difficult to implement. Illness, especially HIV/AIDS, TB, and malaria have adversely affected the labour force and in turn the quality of education in schools given that both teachers and pupils are affected (Mutahi 2007).

Traditional beliefs and attitudes influence health practices with some families, for instance, access to immunisation, while others would rather treat a child's illness using untested herbal medicine. Moreover, disability is often viewed as a 'curse'. In Sierra Leone and Kenya, there still exists some gender bias in provision of education with girls and disabled children given second chance. At

the same time, early marriage affects girls' education especially since some parents want the bride price from marrying off the girls. A disabled girl child therefore faces double barriers. Poor infrastructure impedes the transportation and mobility of children with physical disabilities to schools and where roads leading to schools are poor, they hinder accessibility for disabled people. Where no bridges exist, certain natural barriers like rivers also decrease access to schools (MOEST, 2004). One of the greatest challenges in the continent is armed conflict experienced in some of the countries, which increase the incidences of disability.

CONCLUSION

In conclusion, it is very important to realise that the human rights aspect of providing quality education for all children, including the marginalised children such as those with disabilities should be a collaborative effort amongst all players in education. It is meant to trigger change in the cultures, policies and practices in order to create enabling learning environments suitable for enhancing equal opportunities and participation within the society. Respecting the various international instruments by translating these guidelines into national/regional laws is a step towards achieving the Millennium Development Goals.

It is also clear from the above discussion that IE implementation can be enhanced through systematic linkage with CBR initiatives. The successes of both depend on each other and IE and CBR should be developed together for maximum effect.

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CHAPTER 10

In search of the community in community based rehabilitation

Sarah Rule, Fiona Poland, Joseph Gona

SUMMARY

Community is a central concept in community based rehabilitation. In this chapter, two types of community, geographical and social, are discussed in relation to CBR. The chapter specifically deals with the various roles communities can play in CBR, including providing a physical base for the project, gate keeping, planning and monitoring implementation. According to a commonly used definition, CBR should be part of general community development. The complexities of this are discussed and illustrated with examples from South Africa and Kenya. The role of communities with regard to CBR and policy development and implementation is complicated. The chapter tries to tease out some of the difficulties of involving communities in policy development and implementation, again with reference to African examples.

INTRODUCTION

The word "community" is an essential component of the term and concept of Community Based Rehabilitation (CBR). In the ILO, UNESCO and WHO (2004, p.2) description of the concept of Community Based Rehabilitation, "community" features twice: both as one of the joint implementing agents of CBR and also as a way of situating CBR – "within general community development".

Despite the centrality of community in the theoretical concept of CBR, in practice there seem to be varying interpretations of who constitutes "the community", as well as such issues as the role of the community in CBR and how "the community" relates to CBR policy-making and implementation. This chapter will examine some of these questions, with particular reference to the practice of CBR in South Africa and other African countries.

CBR was formalised in the late 1970s and the early 1980s by the World Health Organisation (WHO) as a form of service delivery to people with disabilities. According to Miles (1994), at this time the WHO conceptualised the community base of CBR as a central and defining component, contrasting strongly with rehabilitation services based at institutions such as hospitals. Here it was more likely seen as catering to an urban elite and residential care which would be less appropriate for supporting participation in the wider community. During this period there was also an increasing support for the view that rehabilitation was the service needed at community level. By the end of the 1980s and in the early 1990s, the official view of CBR from the three United Nations bodies - ILO, UNESCO and WHO - began to include the concepts of community development, social integration and the equalisation of opportunities for people with disabilities. This is reflected in the 1994 definition of CBR as: "a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of people with disabilities" (ILO, UNESCO and WHO, 1994, p.4). As CBR conceptualisation developed further, the issues of human rights, poverty alleviation, inclusive communities and the role of disabled people's organisations came to be included in the Joint Position Paper on CBR (ILO, UNESCO and WHO, 2004). Inclusive communities are identified as those which will adapt to the needs of people with disabilities and take an active role in overcoming the barriers that people with disabilities face in society.

WHO IS THE COMMUNITY INVOLVED IN CBR?

This brief historical review of the development of the concept of community in CBR perhaps points up how the role envisaged for community in recent times, has become more active and encompassing, moving from simply being the base for the provision of rehabilitation services, to actively removing barriers for people with disabilities. This may beg the question, 'Who is the community who will be removing barriers and implementing CBR?'

Webster's Dictionary (Gove et al, 1990), sets out two pertinent definitions of community. The first one, "a social group of any size whose members reside in a specific locality, share government, and often have a common cultural and historical heritage" underlines a community's geographical connections. The second definition of community perhaps especially useful when considering CBR, is "a social, religious, occupational, or other group sharing common characteristics or interests and perceived or perceiving itself as distinct in some respect from the larger society within which it exists". Here, the emphasis is placed on shared characteristics, such as experiencing a disability.

The Joint Position Paper on CBR (ILO, UNESCO and WHO, 2004) seems to evoke the geographic sense of community in making reference to CBR as involving the collaboration of people with disabilities, their families, concerned citizens and community leaders. In practice in South Africa however, CBR projects often focus on the community of people with disabilities, including their family members. In this context, if people with disabilities are enabled to access counselling, are made aware of their rights and home visits are conducted to help people with disabilities function independently, then a CBR project may be considered successful, even though it has not involved community leaders and other citizens. This definition of success is especially likely to be accepted when a CBR

project is overseen by the government Department of Health. In neighbouring Namibia, however, some CBR workers have made an effort to develop local committees which will involve the wider community and local experts on particular issues. In Kilifi, Kenya, community engagement in CBR activities is being promoted through community representatives. These community representatives are elected by the community and facilitate the involvement of the community in CBR programmes. Similarly, there are other CBR projects in South Africa (some illustrated later in this chapter), which have primarily used the geographic sense of community and have thus collaborated with community leaders and other (non-disabled) members of the community.

In order to identify who should be involved in a CBR project (the community of people with disabilities or the wider community), it is also necessary to look at what the roles of the community are within CBR, as providing a physical base, in developing CBR programmes and priorities, and in building inclusive communities.

THE ROLES OF THE COMMUNITY IN CBR

One role of the community in CBR may be seen as being to provide a physical base from which the CBR service may be provided. In most CBR programmes, being based in the community also means that the community provides at least some of the CBR workers to work in that geographical area. This can be seen in the approach of Helander, Mendis, Nelson and Goerdt (1989), which includes local supervisors, and which has been implemented in many parts of the world. When a CBR project views the community's role as being there simply to provide a physical base and personnel for the project, the function of community participation in the project may be to contribute their resources towards achieving a particular goal or 'the common good' (Boyce and Lysack, 2000). This type of community participation may be common in top-down approaches

to CBR, where a CBR programme is initiated by government departments. In other words, the CBR programme in this setting is community-located rather than community-based. In parts of KwaZulu Natal in South Africa, and in Kilifi, Kenya, some projects call themselves CBR projects while having a hospital base and CBR workers who travel monthly or weekly to various clinics in the community to provide services. The CBR workers generally come from the district that they are serving, although not necessarily from the specific communities that they reach out to. It may be questioned whether this constitutes community based rehabilitation, or might better be defined as a community outreach service.

In a research project examining the training of CBR workers, which was conducted with CBR workers in South Africa between 2003 and 2006 (Rule, 2008), one of the participants specifically highlighted the role of community leaders and other community members as gatekeepers to the community. As she indicated from her experience of working in a rural community in KwaZulu Natal:

'*You can't go out to the community without meeting the stakeholders because you need to sit down with the stakeholders, explain to them what is it that you've got, what you're here to do, how are you going to do that. You first need to explain everything to them. Then you can go out.*' (CBR worker F).

If CBR workers ignore the role of community leaders and others as gatekeepers, the CBR project in that area may be marginalised because it does not have the official sanction of the recognised (and often highly respected) leaders in that community. Community ownership of a CBR project may well only be possible if community members and leaders have initiated or given the go-ahead for the project. In the KwaZulu Natal province of South Africa with its history of immense political tensions and violence, the community's role as gatekeeper has taken on an even more serious note. One CBR worker received threats to his personal safety with warnings not to visit the homes of his clients in a certain area, because he

was perceived to be bringing messages from an opposing political party.

Another role is the central involvement of community as underlined by ILO, UNESCO and WHO (2004), in the planning, implementation and evaluation of CBR programmes. Several questions arise as to the practical implementation of this recommendation in the Joint Position Paper. Firstly, in which sense are they referring to community in this context- the geographical, wider community or the community of people with disabilities? The concerns and knowledge of these two groups may be somewhat different and a CBR project would certainly benefit from engaging both people with disabilities and other key community members in planning, implementation and evaluation. A second question then arises, "How can the community be involved in planning and implementation when CBR programmes are initiated and implemented by government departments?" If, as is the case in most South African CBR projects or programmes, a government department has implemented a CBR programme in a province or district, there are usually policies, documents and norms in place, which guide the implementation of the project. This calls into question as to how much say community members and leaders can actually have in planning a CBR project. At worst, they may be a rubber-stamping group, with little chance to determine the direction of the CBR project outside the government policies, guidelines and norms. In Ethiopia, CBR projects are required to hold community consultation meetings before they are initiated. Here it appears that the community could have a more central role in planning CBR projects. Nonetheless, it is also the case that in rural areas in Ethiopia, it is much harder to bring people together and to educate them about CBR to help community initiation of the project. Another drawback of community initiation of CBR programmes is the effect of local perceptions of what could have caused the disability. In Kilifi, Kenya, studies have established that in some

cases, disabilities are seen as a punishment from God for incest or bad blood, a result of engaging with evil spirits or witchcraft (Gona et al, 2006, El Sharkawy et al, 2006). In such situations, CBR is not really considered as a solution to disability; after all, what can CBR do about such powerful things? People may look for divine solutions, while the community in some extreme cases isolate the disabled person to avoid the wrath of dead ancestors which could be evidenced through long draughts, hunger or break - out of epidemics.

Where a government department is responsible for the CBR programme, questions can then be asked about whom the CBR worker should be accountable to. In an ideal situation, the CBR worker will be clearly accountable to the community, comprising both people with disabilities and also the broader community which they serve. However, if a government department is responsible for paying the salaries of these CBR workers or supplying the resources for the CBR project, then it looks more likely that the CBR worker will be primarily accountable to that government department. This could cause particular problems if the government department and community committee do not agree about aspects of the CBR programme. In a few areas of South Africa, there are CBR forums whose role is to guide (plan and to a lesser extent to implement) CBR in those communities. Here, the CBR worker is at least in part accountable to the CBR forum which may consist of local leaders, people with disabilities and key people from government departments such as health or education. However, even where there is a CBR forum, the CBR worker who is employed by the Department of Health may be called upon to participate in a polio vaccine campaign or in weighing undernourished children, even though the community may have determined different CBR priorities for that time.

Another role of the community in CBR, according to ILO, UNESCO and WHO (2004, p.6) is that "communities adapt their

structures and procedures to facilitate the inclusion of people with disabilities". In this sense of community, it is the broader, geographical community that needs to adapt its structures and procedures. People with disabilities are a marginalised group in almost any community and therefore, in the absence of a strong spokesperson or an active disabled people's organisation, it is unlikely that such a community will of its own accord, adapt to the needs of people with disabilities. It can be the role of a CBR project to encourage the development of an inclusive community as described above. However, it is important that people with disabilities are encouraged to speak out for themselves and their needs, rather than an able-bodied CBR worker doing this. In Uganda, they have found the need to include blind people in CBR posts and in politics, otherwise people with disabilities may not be effectively included in the programme and the community may not become fully accessible.

CBR PROJECTS AND COMMUNITY WORK

According to the definition of CBR set out by the ILO, UNESCO and WHO (2004), another aspect of appropriately developing the relationship between the community and CBR is that CBR should be integrated into general community development. In practice, this has happened in some CBR projects in South Africa, although certainly not in all CBR projects. In KwaZulu Natal in South Africa, there have been innovative developments where, through the intervention of the CBR worker, people with disabilities have been integrated into the local community policing forum as well as into local development committees. In one community, the CBR worker was requested to get involved in a water and sanitation project to ensure accessible water and sanitation facilities for people with disabilities in the area. In Kilifi, Kenya, a participatory integrated development (PID) approach has been used, to facilitate the engagement of the community in development agendas within the

community development framework. In some of the projects, people with disabilities were named in the formation of the inter-disciplinary PID teams capable of leading the community through the PID circle (initiation and awareness creation; situation analysis and visioning; capacity building and planning; implementation and sustenance; monitoring and evaluation). Projects initiated through PID were to benefit everyone in the community regardless of any limitation

The Association of the Physically Disabled of Kenya (APDK) has tried to integrate the CBR programme it manages in Kilifi into the community development workplan. Chiefs and their sub chiefs have been used by the APDK CBR team to facilitate the integration of the programme by sensitising the community to know that every disabled person has the right to get some sort of rehabilitation. Not much success has been achieved; however, a number of people with disabilities have benefited from this programme. Some disabled people have been given prominent roles in assisting the local chiefs in work related to disability issues.

A community-based organisation, World Grace 2001 is also engaged in sensitising people with disabilities through the promotion of spiritual guidance and an inclusive development approach, to come together to advocate for their rights in Kilifi. World Grace 2001 has brought together groups of people with and without disabilities, to come together and meet the challenges of life as a team. Poverty alleviation and rehabilitation within the community are the main agenda of World Grace 2001.

In Kibwezi, Kenya, CBR programmes have been merged in the community development plan. People with disabilities have taken up positions in the local District Development Committees at divisional and district levels. Community support groups have been formed. Members in these groups include disabled people, their families and community people.

In order to bring CBR into the realm of general community development, it is necessary to examine whether CBR workers are adequately trained in community development issues. In the literature it is apparent that while CBR managers and some mid-level CBR workers may have some training in community development, few, if any, CBR grassroots workers receive training in community development issues (Mendis, 1995; Thorburn, 1994; Valdez and Mitchell, 1999; Wirz, 2000). If the frontline (often grassroots) CBR workers are not made aware of the links between community development and CBR in their training, it is unlikely that CBR will become a strategy within general community development. An essential aspect of bringing CBR into the general community development agenda is that CBR should benefit the bigger population. Most of our CBR programmes in Africa are in the rural areas which are badly hit by poverty and high levels of illiteracy. CBR workers should be able to assess the situation and know how to strike a balance.

Community development is often inter-sectoral in nature, with the emphasis being placed on different sectors such as health, water and sanitation, transport and education, at different points in time. In South Africa, one of the difficulties of CBR becoming involved in general community development stems precisely from the challenges posed by such inter-sectoral work, when the CBR worker is employed by or responsible to, a government department which represents just one of these sectors. There are often no inter-sectoral budgets and the department employing the CBR worker may not recognise their use of time and resources in another sector as having value.

One reason why CBR projects need to get involved in work with the broader community and not just the community of people with disabilities is that interventions to promote and develop an inclusive society can fail unless the community at large is aware of disability

issues. An example of this from South Africa is in the field of inclusive education. In one school in Durban, there was a marked drop in enrolments at the school when the parents found out that the school was to include some learners with disabilities. So many parents of able-bodied learners withdrew their children from the school because of their negative attitude towards disability, that there were five empty classrooms. If there had been a CBR project to address the attitudes of the broader community towards disability and inclusion, this may have helped to prevent such a situation from arising.

Another benefit of CBR projects working with the community is sustainability. If ownership of the CBR project resides in the community and the skills have been shared with community members, the project is not doomed to failure if the CBR worker leaves. In such a situation, it may be possible for the community to select people to take on the role of the CBR worker or to carry on this work until such time as a new CBR worker is appointed. One community in South Africa demonstrated their ownership of the CBR project by demanding from local government structures and the Department of Health that they should employ a new CBR worker after their CBR worker had moved.

By working with the broader community, CBR projects can also help to initiate structures and processes to respect the rights of people with disabilities which may have a far-reaching impact. An example of this is in the community of Richmond in South Africa, where the CBR worker has run workshops and worked with community leaders and people with disabilities, to make them aware of the UN Convention on the Rights of Persons with Disabilities. Following this involvement of CBR in community work, the Richmond municipality is preparing to set up a committee that will monitor the implementation of the UN Convention in their area. The local disabled people's organisation has also been given an office on municipal property.

QUESTIONS ABOUT POLICY IMPLEMENT-ATION, CBR AND COMMUNITY

A variety of difficult issues can arise when CBR becomes more formalised and regulated by policies or guidelines. Of course, if a CBR programme is funded and supported by any level of government or even an international non-government organisation, there needs to be some degree of regulation as to what will be supported and what should happen in the project. However, this may raise specific problems in the relationships between the CBR programme or project and the community. For example, how can a CBR policy or guidelines regulate community involvement in CBR when the aim is for the community to initiate and control the CBR project? Does community participation then get relegated to the level of simply contributing their resources to the project or can there still be room for community participation leading to the empowerment of the people involved (Boyce and Lysack, 2000)?

In some countries there may be some confusion as to whether CBR is a philosophy, a strategy or a service. In South Africa's National Rehabilitation Policy, CBR is described as a philosophy which guides rehabilitation. A philosophy is a set of ideas which does not necessarily require human or physical resources or any kind of implementation plan. In this case, it may be asked what the role of the community will be. If CBR is a philosophy guiding all rehabilitation, then perhaps the community should be involved in evaluating whether all rehabilitation (institutional and any other) is in line with the principles of CBR. This certainly does not happen in South Africa.

A related question concerns the level and type of community involvement in monitoring policy implementation in CBR. Although the notion of community may refer to a localised geographical community as well as to a community of people with similar characteristics (e.g. disability), monitoring CBR policy

implementation at a national or possibly provincial level would seem to preclude the involvement of localised geographical communities. Monitoring CBR policy implementation at a local level would seem to include members of the disabled community as well as members of the broader community. There is also a question as to the role of local communities in drawing up CBR policies, which will be applicable at a provincial or national level. Although it is possible to consult local communities with careful facilitation, in our experience in South Africa, CBR policy development at a provincial and national level usually only happens with consultation of the community of people with disabilities. This then means that when a CBR policy has to be implemented at a local level, the broader community has had no say in what needs to be implemented.

A final question relating to policy implementation, CBR and communities is that of how accountability to 'the community' should be enacted by policy makers. The concept of CBR gives community a fundamental role in the implementation of CBR and yet, a centrally or provincially-determined CBR policy should not regulate the methods of community accountability and involvement, if the community is truly to be an equal and self-determining partner in CBR.

CONCLUSION

As can be seen from the issues examined in this chapter, the nature of community involvement in CBR practice is not uncomplicated. Any specific CBR programme needs to decide who they will involve in their programme from the community of people with disabilities and their families and/or the broader community, including community leaders and other interested citizens. The role that the community plays in a CBR programme may include being gatekeepers to the community, planning, implementing and evaluating CBR, and adapting structures and processes, in order to

become an inclusive community. When defining the role of communities in CBR policy, there are many questions to be considered. While examining these issues carefully will pose challenges, building recognition of what specific relationship between community and CBR programme will be most appropriate can certainly be seen to be important in the practical implementation of community based rehabilitation.

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CHAPTER 11

Disability, HIV and AIDS: a need for social inclusion and equalisation of opportunities

Paul Chappell, Kennedy Akolo

SUMMARY

The HIV and AIDS pandemic is being most felt in sub-Saharan Africa. Interestingly though, little is known about the impact of the pandemic on children and adults with disabilities, even though they are likely to be at increased risk of HIV infection. This chapter explores some of the extrinsic factors that increase the vulnerability of people with disabilities to HIV. It also examines the reasons for their exclusion from HIV and AIDS services. The chapter sets out how, through a collaboration between community structures, HIV services and government officials, CBR can provide an effective strategy for the prevention and management of HIV and AIDS.

INTRODUCTION

The HIV and AIDS pandemic is without doubt a serious global health threat which is being most felt most in sub-Saharan Africa. According to the UNAIDS (2007), of the estimated 33.2 million adults and children who are infected with HIV worldwide, 22.5 million are living in sub-Saharan Africa. Coincidently, South Africa now has the highest rate of infection globally with an estimated 5.5 million people living with HIV and AIDS (Table 1).

Table 1: Top 5 Countries by Number of People Living with HIV/AIDS in Africa (end 2006)

South Africa   5,500,000

Nigeria   2,900,000

Mozambique   1,800,000

Zimbabwe   1,700,000

Tanzania   1,400,000

Source: UNAIDS (2007)

We know that the HIV and AIDS pandemic has had particular impact on vulnerable populations, such as women and children. For example in South Africa, young people, especially young women between the ages of 15-29 years, have the highest rate of infection in the country (Pettifor, 2004; UNAIDS, 2007). However, very little is known about the impact of HIV and AIDS on people with disabilities despite the fact that they are considered to be one of the world's most vulnerable populations. This is quite surprising taking into account that the risk factors associated with disability such as poverty, social stigma, unemployment, poor access to education and health care – are similar to those for HIV (Groce, 2005).

So why is it that people with disabilities continue to be overlooked when it comes to HIV? Furthermore, how can CBR rise to the challenge of the HIV and AIDS pandemic? This chapter sets out some of the contributing factors for this exclusion and gives an example of how a CBR programme in Kenya incorporated HIV and AIDS into their work.

'No sex please, we're disabled'

Throughout the world there is a widespread belief that people with disabilities are perceived to be asexual (Shakespeare et al, 1996;

Anderson and Kitchin, 2000). Considering that sexual contact is the most prevalent cause of HIV in Africa, people with disabilities are presumed to be at very low risk of contracting the virus (Swartz et al, 2006). These perceptions have had negative consequences for the disabled population. For example, Collins et al (2001) found that children with disabilities were less likely to receive science and health education and were often excluded from sex education classes. Furthermore, very few of the national HIV campaigns (e.g., Lovelife in South Africa) target or include people with disabilities. As highlighted by Groce (2006), where HIV educational campaigns are on radio or television, groups such as the deaf and the blind are at a distinct disadvantage.

To add to the equation, many of the HIV and AIDS treatment centres and family planning units are physically inaccessible (Groce et al, 2006) and many health workers have a negative attitude towards dealing with sexual issues and people with disabilities. In Zambia for example, women with disabilities reported having attracted a lot of negative attention whilst attending reproductive health services, which inevitably discouraged them from using such services (Smith et al, 2004).

The notion of asexuality is really only a myth. People with disabilities around the world are sexually active. With the lack of sex education though, many people with disabilities are putting themselves at high risk of HIV. For instance, Jackson and Wallace (1999) found that women with disabilities were less likely to get married and were more likely to have multiple sexual partners than their non-disabled cohorts.

In certain communities around Africa and Asia, there is a widespread belief that HIV can be cured by having sexual intercourse with a virgin. This concept of 'virgin cleansing' combined with the myth of asexuality means that many children and adults with disabilities are more prone to rape and sexual abuse compared to their non-

disabled peers (Yousafzai et al, 2004).

Unfortunately, many CBR programmes and disability organisations still fail to address the issues of sex and sexuality. This could be attributed to the fact that in being so focused on eradicating the social barriers of inaccessibility, poverty and injustice, they have forgotten one of the simplest of human needs - sex.

GENDER, DISABILITY AND HIV

Given the low status often attributed to women in many societies, it is well known that they are more prone to HIV than their male counterparts. The situation for women with disabilities is even more difficult. For instance, women with disabilities are three times more likely to be raped than non-disabled women (Groce, 2005) and although women with disabilities are seen as potential sex partners, they are often perceived to be unmarriageable and unable to have children (Yousafzai and Edwards, 2004). This misconception, along with the low opportunities for education and employment, means that women with disabilities find themselves in positions of being unable to negotiate safer sex. Furthermore, the fact that many women with disabilities are living in extreme poverty (DFID, 2000) could be a contributing factor to why some turn to sex work as a means of survival.

STIGMA - A COMMON IDENTITY?

Throughout Africa it is well known that stigma drives the HIV and AIDS pandemic. The fear of being 'trapped' by an unwanted disease that causes isolation, prejudice and reduced socio-economic opportunities, prevent many from coming forward to be tested for HIV (Swartz et al. 2006). In respect of this, HIV and disability share a common adversary, that of stigmatisation. Just like those living with HIV and AIDS, people with disabilities are also feared

and misunderstood. For example, in some communities in South Africa, children with disabilities are hidden away not only out of shame, but also with the fear of 'contaminating' other able-bodied children with an 'unwanted disease' (Chappell and Johannsmeier, 2007). Taking this into account, it could be argued that being disabled and having HIV and AIDS could be seen as a 'double stigmatisation'.

The disability rights movement has made progressive steps towards eradicating stigmatisation by shifting the focus of disability from an individual medical construct towards the social and political barriers that prevent people with disabilities participating as equals in their communities (Oliver, 1993). Likewise, HIV and AIDS activists have taken a similar stance in an attempt to show that those living with HIV and AIDS are not dangerous or inferior.

Considering these similarities, is it possible for the disability movement to work alongside HIV and AIDS activists? Some may argue against this as in most societies, people living with HIV are not classed as 'disabled' until their CD4 count is low and they are very sick. In view of this some people with disabilities may worry that being identified as allies of people living with HIV and AIDS may push them back into the realm of the medical model from which they have worked so hard to remove themselves (Tataryn, 2005). Whatever the answer is to this question, the fact still remains that people with disabilities are at great risk of HIV.

HOW CAN WE MEET THIS CHALLENGE?

The issue of HIV and AIDS is an issue of basic human rights and public health and as stipulated by Groce et al (2006 p.4), 'the inclusion of individuals with disability in HIV/AIDS outreach efforts simply cannot wait until all other groups in the population are addressed'. As highlighted throughout this book, CBR is an

effective strategy in raising the profile of disability and nurturing a more positive community response. Its focus on social inclusion and equalisation of opportunities provides valuable lessons which could be utilised for the prevention and management of HIV and AIDS.

Nganwa et al (2002) previously outlined that CBR should be an entry point for people with disabilities to access HIV and AIDS programmes. This entails challenging existing CBR and HIV and AIDS projects to work in partnership together and consider issues of disability and HIV within their prevention campaigns and awareness raising programmes, e.g., leaflets in Braille, posters that include sign language, physically accessible Voluntary Counselling and Testing (VCT) sites etc., and for community members to promote and share the information appropriately.

REFLECTIONS OF CBR AND HIV IN KENYA

The feeling from Kenya is that there is need to elevate the CBR strategy to enhance its role within the various sectors of health, education, social, economic and political life. For meaningful impact, CBR needs to be systemically embedded in policy and programming. These considerations determine whether CBR can effectively impact on inclusive HIVand AIDS strategies .

In general and using Kenya as an example, there is a slow uptake of CBR by all the population and addressing the needs of people with HIV and AIDS remains outside the core of most programmed CBR interventions. The complex status and weak infrastructure of CBR in Kenya makes it doubly difficult to have initiatives that include HIV and AIDS.

POTENTIAL IN CBR

This does not mean that CBR does not have the potential to be an

effective tool for the inclusive development of people with disabilities and the capacity to respond and pool together all interventions. This process is described in the previous sections of this chapter. The complexity of CBR mirrors the complexity of issues that affect the life of people with disabilities and in this way makes it a potentially effective interventnion strategy.

In Kenya communities have demonstrated the capacity to manage issues in an integrated way. Community members do not have to finish one chore before embarking on the next but implement them concurrently. As a strategy, the CBR approach has the flexibility to penetrate other sectors with a bottom up approach and at the same time benefit from the top down approach.

INTERVENTION FOR SUCCESS: OVER COMING THE BARRIERS

• **Resources and political will**

There is however, need for specific action on important issues such as proper resourcing and positioning of CBR as a critical actor in the community. Currently most of the CBR groups in Kenya have very low capacity and lack government support.

• **Training**

In order to be successful, there is need for capacity building on inclusive disability and HIV and AIDS for CBR teams, Government officials, NGOs and donors.

• **Lack of research information**

There is a need to gather and provide evidence-based information on the process of including people with disabilities and HIV and AIDS into CBR programmes and other support systems.

- **Ensure inclusive programming**

Positioning and profiling CBR as a key strategy for improving the lives of people with disabilities and HIV and AIDS.

- **Access to information**

Ensure effective access of HIV and AIDS information, services (prevention, testing, treatment, care and support) to people with disabilities in all formats and modes

- **Use of media**

Tap into the power of the electronic and print media, towards attitude change in society and influence inclusive policy in disability and HIV and AIDS.

CONCLUSION

The issue of disability and HIV is a matter of human rights that needs to be urgently addressed by both the disability movement and HIV and AIDS services alike. HIV and AIDS initiatives will succeed in their task of addressing/reducing HIV more effectively if they join with CBR programmes because:

1. CBR is already in the community and has the potential to address the needs related to social exclusion and participation.

2. People with disabilities are faced with many similar issues as those living with HIV and AIDS e.g., stigma, poverty, social marginalisation etc.

3. CBR can provide and facilitate the expertise needed to communicate better with people with disabilities and this will in turn help HIV and AIDS programmes access this vulnerable part of the population more effectively.

Nevertheless, many countries in Africa, for example Kenya, find it difficult to resource and structure CBR programmes generally, and

this make it difficult to include people with HIV and AIDS together with people with other impairments.

CBR programmes will succeed in their task of supporting people with disabilities and their families more effectively, if they link with HIV and AIDS programmes. For instance, HIV and AIDS programmes could help CBR programmes address issues of sexual equality and abuse amongst people with disabilities. Furthermore, funding for HIV and AIDS initiatives are much stronger than for CBR, therefore, linking the two programmes could increase resources for CBR programmes.

CBR needs to be braced to tackle HIV and AIDS through recognising its advantaged position as a community owned and driven tool but also its vulnerability if under resourced, under capacitated and if it remains in the periphery of sector programming.

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CHAPTER 12

Sign language and Community Based Rehabilitation (CBR)

Robert Nkwangu.

SUMMARY

This chapter looks into the inclusion of Deaf[9] persons in CBR programmes. It emphasizes the importance of sign language as a means of eradicating barriers to the inclusion of Deaf persons in this process. The chapter highlights the shortcomings faced by previous interventions in trying to implement CBR programmes for Deaf persons and from a Deaf person's perspective, provides a way forward.

INTRODUCTION:

The World Federation of the Deaf (WFD) estimates that there are about 80 million Deaf persons and hard of hearing people in the world. Of these, about 80% are found in developing countries and more than half of them are in Africa. WFD (1992). WHO estimates that 2/3 of the deaf and hard of hearing people live in less developed countries. WHO (2001 & 2005 2006). In Uganda, however, disabled people are estimated to account for about 4% of the country's population. Of this, deaf people represent about 15%, people with physical impairments – 35.3%, spine injuries – 22.3%, people with sight problems – 6.7%, people with mental difficulties– 7.2% and others – 9.6%. UBOS (2002). However, there are some inadequacies in data collection which make it difficult for all persons with disabilities (PWDs) to be enumerated.

To achieve the Millennium Development Goals especially reducing poverty, limiting the spread of HIV/AIDS and providing Universal Primary Education for all, the problems of Deaf people will need to be identified and solutions implemented. CBR is one of the ways for improving the quality of life of Deaf persons through provision of rehabilitation services which promote their integration in all spheres of life and influence.

DEAF PEOPLE AND CBR – EXPERIENCES FROM UGANDA:

In Uganda, the disability statistics show that approximately 15% of people with disabilities are deaf (UBOS 2002). Deaf people tend to be excluded from all social activities and even their own parents and family members are unable to communicate with them in a language that they both understand. Some families do not bother to seriously ensure that their basic needs, like access to education, are taken care of. This seriously violates their human rights, although many Deaf friendly laws and policies have been enacted by the Ugandan government in recent years. A good example is the inclusion of sign language in the constitution of Uganda (UG 1995). Other examples from Uganda are the PWDs Act (UG 2006) which also provides for recognition of sign language and provision of interpretation services. The Uganda Communications Act of Uganda (UG 1998) also calls for provision of services friendly to Deaf

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[9]   A capital 'D' '**Deaf'** is used when referring to the **social aspect** of Deafness – a group of people / an organized group – the same as when you refer to the Baganda, Zulu, English, French, Luo, Aborigines, etc. in this case, we cannot use a small letter for these (zulu, English, French, luo, etc). a small 'd' for '**deaf'** is used when referring to the **biological aspect** of deafness or medical aspect – e.g. malaria, cough, pregnant, deaf, etc.

people, like sub-titles and sign language interpretation on important broadcast television programs. The National Policy on Disability (UG 2006) advocates for the recognition of sign language as an important language of communication for a part of the country's population. International instruments including the UN Convention on the Rights of PWDs (UN 2006) also serve as instruments of change for the betterment of Deaf people and their families.

Deafness is predominantly a social problem. Politically, socially and economically Deaf people tend to be excluded from important development programs. This is mainly due to the communication barrier that exists between Deaf and hearing persons. As a result, Deaf people are not able to effectively participate in programmes that could be beneficial for their wellbeing. They end up being poor, illiterate, uneducated and face various health problems. The inability to communicate also means that Deaf people lack access to important information yet CBR programs depend on sharing information and learning from each other. Owing to these and many other factors, interventions to avert the problems of Deaf people tend to be very expensive, yet they are hampered by the inadequate resources.

In the light of this it is not surprising to find that many CBR projects and programmes in Africa tend to ignore issues of the Deaf, partly due to ignorance and partly due to negligence. This is mainly because most CBR personnel who would have otherwise taken center stage in finding long-term solutions to the problems of Deaf people, are themselves not fluent in sign language so that they are better able to communicate directly with the Deaf people in need of their services. This therefore calls for serious intensive sign language training for CBR practitioners in addition to the employment of professional sign language interpreters to aid in the delivery of CBR services to the Deaf.

For a successful CBR programme, there is need for information

sharing, experiences and identification of new tactics to alleviate problems faced by PWDs (WHO 2003). Here Deaf people have been left out. The information does not reach them in the best possible way. There is therefore need to focus on activities and innovations that will promote optimal inclusion of Deaf persons in CBR programs. Also Deaf people should be consulted whenever there is a CBR programme being designed, hence the saying, "nothing about us without us". Credit goes to CAN for accepting to publish this chapter - a good example of consultation.

CBR is a relatively new experience for the Deaf people, as until recently they have rarely been included in CBR programmes. This is changing now as more CBR workers gain understanding of Deaf people's issues and gain proficiency in sign language. Consequently it's clear that there is a considerable change in the approach of CBR for the Deaf people like for the other people with other disabilities. However, the Deaf have remained the minority group in CBR initiatives. At the recently concluded 3rd CBR Africa Conference held in Johannesburg, South Africa, of the over 268 delegates, only two Deaf people from one outside country (Uganda) managed to participate, only three from the host country attended (5 Deaf people in all). The question is where were the rest? Were they not interested or did they not hear about the conference? Or did they receive information about it, but simply had no interest and thought that there was nothing available for them? It would seem that CBR programmes will be more inclusive and more effective if they were managed in such a way to equitably include all categories of persons with disabilities (PWDs) and also address their needs equally. In case there are some programmes in Africa which have attempted to target Deaf people, then there are limited benefits realized and one cannot rule out the possibility that the few and limited benefits might be partly due to employing the wrong staff. Such staff might not have been adequately trained to work with Deaf people. Such people might also lack experience in

deafness related issues and it is of no doubt that these people cannot even sign the alphabet or count up to 10 in sign language! An argument here is that there should be adequate sensitization of CBR personnel in deafness related issues. Partnerships with National Associations of the Deaf will in this case be important since they attempt to reach more of their members than any other. It also necessitates the need for intensive sign language training for all personnel involved in community based rehabilitation of PWDs, if the Deaf communities in their areas of operation are to benefit and to achieve this there is a need for serious involvement of Deaf people themselves.

Some traditional CBR programs targeting PWDs are too general and do not take into account the unique interests of Deaf people. This therefore necessitates the need to strengthen the hearing impairment component of CBR. To find a solution to this, programmes should involve Deaf people themselves in planning, implementation, monitoring and evaluation of some of the activities, since their problems are best known to them.

For a long time, rehabilitation services have been based in the health sectors of nations. To the Deaf people in Uganda, these services are however fragmented. For the deaf people, hearing aids and/other devices are often required – yet its clear, basing on personal experience and testimonies from other Deaf people, that not all deaf persons can effectively use these aids. More over, these devices are not affordable to most of the typical Deaf Africans and Deaf people in the less developed world. It is also important to note that the medical model of rehabilitation, where the focus lies on curing impairments tends to demean the importance of sign language as the language for Deaf people, yet it enhances their inclusion in the communities in which they live.

In Uganda, the objective of CBR activities being implemented by the Uganda National Association of the Deaf (UNAD) is to enable

Deaf people to attain an optimal inclusion and participation in their community, so as to realize their full mental and physical potentials. UNAD is implementing a set of specific activities focusing on inclusion of the Deaf in the entire CBR program. We can call UNAD's intervention as supporting or facilitating the hearing impairment component of CBR. The main focus here is on Deaf children, their families and service providers and aims at ensuring that there is effective communication between Deaf people, their families, community members and service providers. Additionally UNAD emphasizes early identification and assessment of deaf children or interventions in their tender life times. This means that early childhood development is a prerequisite for ensuring that such Deaf people are able to develop their mental and psychological wellbeing so that they can ably access rehabilitation services. By improving communication between the Deaf people and the hearing communities, it is envisaged that Deaf people will be able to access mainstream services within the overall CBR framework.

From UNAD's experience therefore, the following issues are worth noting as far as CBR is concerned:

1. Deaf Associations are of utmost importance in providing the expertise and competence needed in addressing CBR issues of concern to Deaf people.

2. The need for Deaf Associations to initiate pilot / model projects that are used as an "eye opener" for government's intervention. The model / pilot project will eventually be taken over by government as a way of ensuring sustainability.

3. UNAD does networking, advocacy, lobbying, awareness and information work specifically for inclusion of Deaf people in CBR programs and generally for ensuring sustained government and community support of CBR programs for all categories of PWDs. Activities should be done in collaboration with government and local rehabilitation officers.

THE ROLE OF SIGN LANGUAGE IN CBR:

Deaf people have their unique needs which differentiate them from other categories of PWDs. Sign language is central to this need and if CBR programs are to be of benefit to Deaf people and their families. It is very difficult to find long term solutions to the problems of Deaf people in education, health, employment, etc., if the issue of sign language is ignored. Thus sign language takes a central and unique role in all interventions aimed at finding long term solutions to the CBR needs of the Deaf people in the communities where they live.

Development cannot be achieved if certain categories of people are neglected. Similarly the objectives of CBR cannot be realized if the Deaf people are left out due to problems with communication. This necessitates recognition of the importance of sign language in CBR efforts for PWDs. Owing to the communication barrier; rehabilitation of the Deaf especially in rural areas is very challenging. It is challenging mostly in the rural areas since these are usually remote and it is very hard to identify Deaf people. More still, cultural beliefs are strong in such areas and Deaf people here are viewed as outcasts to the extent that they are hidden away from the services for fear of bringing shame on their families and/ or guardians. It takes time to sensitize such communities. However, the urban areas should also not be ignored.

Sign language is a visual, gestural language and involves among others the use of hands, facial expressions and body movements. Sign language has its own grammar which differentiates it from other written / spoken languages. Sign language keeps on changing overtime, as ages go on, new signs develop. Sign language is not uniform all over the world. For many deaf people, sign language is their first language i.e. their mother language and it varies from country to country. This language therefore is the surest way of

enabling Deaf people to acquire knowledge and express themselves in the communities where they live. It bridges the communication gap between Deaf and hearing people.

Sign language is not only a language for the Deaf, but it's also a method that can be used for rehabilitation, a component of CBR. A CBR programme without the capacity to use sign language is like CBR without a strategy for the Deaf. There ought to be training in sign language for various categories of personnel / individuals within the overall CBR framework including the Deaf people themselves, their families, community members and other service providers.

In Uganda, Deaf volunteers are employed in the communities and are assisted by sign language interpreters and development workers. These work hand in hand with the government / District Rehabilitation Officers.

In the general population there is a lack of a clear understanding about the needs of people with deafness and this is reflected in many of the programmes that exist. An example of this can be seen by the many special schools for the Deaf people which have been set up in cities all over Africa. It is worrying that these people do not join schools in their villages / communities, as highlighted by the UN Convention and in the objectives of CBR. The answer might be that deaf schools are well equipped and are of better 'quality', providing almost everything the Deaf people need. Would it not be better if the huge monies spent on these institutions (buying playing devices / gadgets, etc) are used to teach sign language to the remote Deaf persons in the deeper villages? It is hard to know whether the said institutions serve the Deaf children attending to them, or if they serve to make them more excluded from their own communities. Or is it the Deaf people who serve the schools by enabling them to get resources to develop institutions when the money could be used in a better way for the benefit of those it was intended for. In light of this argument, numbers of Deaf people are used as indicators to

secure resources; yet the fact is that the resources are not always put to proper use in line with the purpose for which they were secured (sometimes also partly due to corruption).

On a positive note, the example of a CBR pilot project in Uganda involving various activities and being implemented by Uganda National Association of the Deaf (UNAD) in Tororo district, is using sign language at the forefront of all interventions. There is training of approximately 300 people in the district and these include the Deaf people, their families, service providers like educationalists, health personnel, and other interested groups. The project also aids two model schools and this is aimed at meeting the education needs of the Deaf people. UNAD facilitates sign language trainers of trainees or community volunteers to carry out intensive sign language training in different sub counties in the model district.

In line with sign language activities, emphasis is also placed on advocacy work to influence the government and other stakeholders within and outside the disability movement, to consider the unique rehabilitation needs of the Deaf persons. There are also awareness raising and sensitization activities which are prerequisites for influencing concerned institutions to mainstream and integrate Deaf people's issues in their CBR programs, plans and priorities. Collaboration with the government especially through District Rehabilitation Officers is an important aspect of the project.

By implementing CBR activities for the Deaf, UNAD has realized a number of important achievements which could act as a lesson for others. These achievements include but are not limited to the following:

• Enhanced communication amongst the Deaf themselves and with the hearing community especially members of their families. This improves sharing of CBR information as it bridges the communication gap.

• Awareness raising about CBR issues of Deaf people especially Sign Language and Deaf culture / Deaf awareness. This has also resulted into change in attitudes towards the Deaf.

• Integration of Deaf people's issues in district / national development programs, plans and projects especially CBR programs.

• Formation of district groups for the Deaf e.g. Tororo Association of the Deaf, Parents of the Deaf Association and other peer groups. These have been trained in initiating and managing projects and they attempt to collectively find meaningful solutions to the problems affecting their members e.g. poverty reduction, education, health, employment to mention a few.

• More opportunities for deaf people in the education sector. Model schools and units for the Deaf have been established and strengthened.

• The trained volunteers who include government and community workers have established sign language training centers where sign language is taught to parents, Deaf people and interested persons. This ensures sustainability of rehabilitation activities for the Deaf.

In the light of progress that has already been made, we still must agree that improving the livelihoods and empowerment of Deaf people using any community based model is worthless if a language which is clearly understandable to them is absent. In order to communicate, there is need for a language, a language which can be understood by the parties involved. This is why we have languages like English, Luganda, Luo, French, Spanish, Zulu, etc and of course Sign Language. Sign Language is a language just like any other – it has its own grammar and vocabulary, its own dictionary and curriculum. Recently, many CBR programs have placed emphasis

on training how to empower PWDs, how to work with community leaders, yet they have put little attention to the importance of training sign language as a pre-requisite for these tasks. This does not lead to rehabilitation of Deaf people, since they fail to receive the message in the best possible way.

Despite a lot of efforts being undertaken by National Associations of the Deaf to rehabilitate Deaf people in their localities using sign language, a lot of challenges still exist. There are insufficient funds to cater for a wide variety of needs of Deaf persons, which means that CBR programs for these people are fragmented in selected areas at the expense of others. Negative attitudes also still exist, some circles prefer only inclusive CBR activities and yet some Deaf people have their unique communication needs. This is why many inclusive CBR programs have not been beneficial to Deaf people.

SUMMARY OF KEY RESOLUTIONS FROM A DEAF PERSON'S PERSPECTIVE:

Based on the above scenario, the following issues are worth noting:

- Sign Language is central if any CBR program is to benefit Deaf persons. Deaf people have their unique communication needs and interests which differentiate them from other categories of PWDs. CBR approaches which might be a success for some categories of PWDs might not cater or be beneficial for the others. It is clear that within the community there are different target groups of PWDs with varying disabilities needs and interests and each group should be approached with flexible strategies.

- CBR personnel ought to be sensitized on deafness related issues and trained in sign language.

- There is need for the involvement and ownership of CBR activities by the Deaf people themselves since their needs

are best known to them. This necessitates the use of Deaf community volunteers to help create awareness and ensure sustainability. These volunteers should also be facilitated morally and financially. Deaf people should also be consulted during design, implementation, monitoring and evaluation of CBR programmes.

- It is also important that CBR guarantees the participation of all people with various types of disabilities. This calls for a combined effort in as far as CBR objectives are concerned.

- Introduction of sign language interpreters within the CBR structure is imperative.

- The role of National Associations of the Deaf (NADs) should not be ignored or underestimated. NADs are instrumental in providing rehabilitation services to their members since their problems and ways of alleviating such problems are best known to them and they reach most of their members. Donors ought to mobilize resources to directly fund CBR projects / activities for Africa's NADs and share information / experiences with them.

- Support to local community associations of Deaf people and parents of the Deaf associations, should be a priority since it will ensure that such associations carry out mobilization and advocacy at grass root level. This also gives the local groups the morale to work even harder and reach more members. There should also be support to peer groups / models for solidarity to carry out their program activities efficiently and effectively.

- Governments should develop policies and guidelines for implementing CBR programs and such policies should benefit all categories of PWDs on an equal basis with special emphasis on the unique needs of each PWD category. Disabled People's

Organizations should influence those policies in their favour. Local governments should network with local Deaf groups / associations in order to meet their rehabilitation interests and mobilize the Deaf and their families to participate in rehabilitation activities.

CONCLUSIONS:

Community development cannot be realized if certain categories of people are left out. Similarly, the objectives of CBR cannot be achieved if Deaf people's needs, interests and priorities are not seriously considered. This necessitates the importance of recognizing sign language in CBR efforts and in equalizing opportunities for deaf people. Sign language enhances the elimination of discrimination, aids in reducing poverty and unemployment, ill health and many other social problems for the Deaf. Being without a language is like without any access to development. Deaf people should be involved in all stages of CBR programs from designing / planning to implementation, monitoring and evaluation and finally to enjoying the benefits of the programs. They should be left to make decisions about what services they need, to enhance their participation. There is also need for donor support directly targeting National Associations of the Deaf and these associations should be left to take the role of implementing and evaluating CBR programs for their members, since such associations attempt to reach more Deaf people than any other group. However, the involvement of the government and other stakeholders should not be ignored and this calls for multi-sectoral partnerships / coordination.

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CHAPTER 13

Introduction to the WHO/ CBR guidelines

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SUMMARY

This chapter reports on WHO's role in the development of CBR. This has included the development of the CBR Training Manual (WHO 1989), Helsinki Review (WHO 2003), CBR Joint Position Papers (WHO/ILO/ UNESCO 1994 and 2004) and most recently, the CBR Guidelines (to be launched in 2009). It is this last development that the chapter pays particular attention to, looking at the purpose of the CBR guidelines, their development, intended use and future prospects.

INTRODUCTION

Though CBR is currently practised in more than 90 countries and is part of many national strategies, it still often follows a vertical approach and focuses on a single sector or domain. For example health with an exclusive focus on physical rehabilitation; or education, with an exclusive focus on pre-primary and primary school inclusion; or livelihood, with an exclusive focus on income generation activities. People's needs are multi-dimensional and human development requires well-being in different domains which include health, education, livelihood, and a positive social and physical environment. To ensure people with disabilities have the possibility of leading fulfilling lives with dignity, CBR needs to adopt a multi-sectoral, comprehensive approach, addressing all the key domains of well-being.

The *CBR Joint Position Paper* (2004) promotes this multi-sectoral, rights-based approach focused on poverty reduction within an inclusive community. However, the question still remains: how do we implement this approach? In response to this question WHO agreed to develop guidelines to help CBR managers develop an effective multi-sectoral strategy encouraging inter-sectoral activities. Concurrent to this development, the United Nations adopted the *Convention on the Rights of Persons with Disabilities (UN 2006).* The Convention has both inspired and informed the development of the Guidelines and the Guidelines can be used as a tool for ensuring that the rights of people with disabilities, outlined in the Convention, are effectively realized in a practical way at the community level.

BACKGROUND

WHO introduced the concept of CBR in the late 1970s. It was designed to enhance quality of life for people with disabilities through community initiatives. To facilitate its implementation WHO published a CBR Manual "Training in the community for people with disabilities" (WHO 1989). This publication outlined how CBR workers could be trained to develop their expected knowledge and skills base. Since this time many versions or models of CBR emerged and many lessons have been learnt, notably the huge importance of the contextual factors and the shift away from understanding disability as a purely medical challenge, to one that incorporates social aspects and rights based issues. These perspectives informed the first version of the Joint position statement about CBR by WHO, ILO and UNESCO in 1994.

On the 25th year of CBR implementation, a review was carried out in Helsinki, Finland in 2003. From the review it was noted that CBR had to address the following issues:

- Community involvement and ownership

- Poverty alleviation –with CBR to be promoted as a strategy to reduce poverty

- Multi-sectoral collaboration – CBR would have to address issues of health, education, labour and social welfare

- Involvement of Disabled People's Organisations at all levels – CBR would promote the involvement of people with disabilities at every level

- Scaling up – looking into up-scaling from small CBR projects

- Evidence based practice to promote CBR

Consequently, the joint position paper on CBR was revised (WHO/ILO/UNESCO 2004) with the aim of promoting CBR as a way to secure inclusive development and human rights for people with disabilities, and as a call for action against poverty. The joint position paper defined CBR as "*a strategy within general community development for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities*". It also emphasized "*the role of Disabled People's organizations as a resource to strengthen CBR programmes*" but also noted the fact that CBR needs to be "*implemented through combined effort of PWDs themselves, organizations and communities and the relevant Government and non-governmental health, education, vocational, social and other services*". With the concerted effort of these different stakeholders the following approaches would be possible:

- A direct link between disability and rehabilitation: for example, not looking at disability as just a product of impairment and promoting rehabilitation services that were agreed upon and not imposed

- Human rights: equal citizenship – there would be equal rights to access healthcare, education, food, shelter, jobs

- Poverty: poverty reduction would be one of the main aims of any CBR programme

- Inclusive Communities: it would be possible to adapt to the structure and opportunities within communities to ensure inclusion of people with disabilities in all social/economic activities

- Role of organizations of people with disabilities: this would help ensure that CBR is planned and implemented with active participation of disabled people and their family representatives

Having come up with a position paper on CBR detailing the ideal features of a CBR programme, there was then need to develop guidelines to help CBR managers develop effective programmes along these lines. In development of the guidelines it was acknowledged that all communities are different in culture, physical environment, political structure and socio-economic conditions and therefore there could never be one model for CBR across the world. However, while contexts and conditions may vary and there are many models for CBR programmes, it was recognised that there is need for a common framework for CBR programmes. The purpose of the guidelines would therefore be to provide support on how to initiate a CBR programme, or how to strengthen an existing CBR programme. They are designed as a practical guide to strengthen the delivery of CBR and promotion of inclusive development. The target group for the guidelines are CBR managers as well as personnel from local and international NGOs, government ministries, development organisations, primary health care programmes and organisations of people with disabilities.

CBR GUIDELINES DEVELOPMENT PROCESS

The development of the CBR guidelines was a consultative process that involved, at the first meeting held in November 2004, 65 participants including CBR pioneers, representatives from UN

organisations, Governments, leading NGOs, Disabled People's Organisations and other professional organisations. As a first step to developing the Guidelines an effort was made to reach a consensus about CBR, its various components and elements. The finalised outline of the Guidelines agreed on a common agenda: "Inclusive development to promote an inclusive society"

Particular efforts were made to incorporate evidence, experts' opinions and diverse experiences of over 25 years from all over the world to ensure the guidelines are a document for practitioners. Participation of people with disabilities, especially from low income countries, was considered as essential in the development of these guidelines. The guidelines were to show how the involvement of people with disabilities, family and community, local government and local leaders is not only possible but very important in meeting basic needs and reducing poverty.

The Guidelines look into creating opportunities for health, education and livelihood, while building capacity among communities to take advantage of legislation, putting in place judicial and political systems, as well as developing different partnerships for inclusive development.

The issues covered in the Guidelines are of concern worldwide. Poverty is a concern for people with disabilities in all countries. Educational attainment and access to employment are just two examples where people with disabilities have less opportunity than people without disabilities. As a result, people with disabilities have far lower than average incomes. It is also well recognized that the situation in low income countries is worse for people with disabilities because they face even greater restrictions in access to livelihood, education, health care, assistive devices and personal assistance. Lack of social protection in many countries makes the situation even more difficult. For these reasons, these guidelines focus more on low income countries.

The guidelines also encourage people with all types of impairments to participate actively in the management of the CBR programme, including setting priorities, planning, training and evaluating the programme.

THE CBR GUIDELINES AND THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The United Nations adopted the *Convention on the Rights of Persons with Disabilities* at the time the CBR Guidelines were being developed. As mentioned before the CBR Guidelines focus on community based inclusive development in inclusive health, inclusive education, inclusive livelihood, inclusive community and an inclusive world. This could be achieved through implementation of the *UN Convention on the Rights of Persons with Disabilities,* the general principles outlined in the 3rd Article being:

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

- Non discrimination

- Full and effective participation and inclusion in society

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

- Equality of opportunity

- Accessibility

- Equality between men and women

- Respect for the evolving capacities of children with disabilities and respect for the rights of children with disabilities to preserve their identities

Education, health, habilitation and rehabilitation, work and employment, adequate standard of living and social protection, are all addressed in other Articles of the Convention. Much as the convention inspired and informed the development of the Guidelines, the Guidelines can also be used as a tool for ensuring that the rights of people with disabilities outlined in the UN Convention are effectively realized at the community level.

THE CBR MATRIX

The CBR Matrix was developed to help CBR managers visualise the range and depth possible within a CBR programme. It shows the key areas of well-being that a comprehensive multi-sectoral CBR programme should cover: health, education, livelihood, social and the empowerment of people with disabilities and their families. Each of the five components (domains), have been divided into elements which a comprehensive CBR programme may address, depending on local circumstances.

Below is a graphical representation of the CBR Matrix:

GOAL : INCLUSIVE DEVELOPMENT - INCLUSIVE SOCIETY
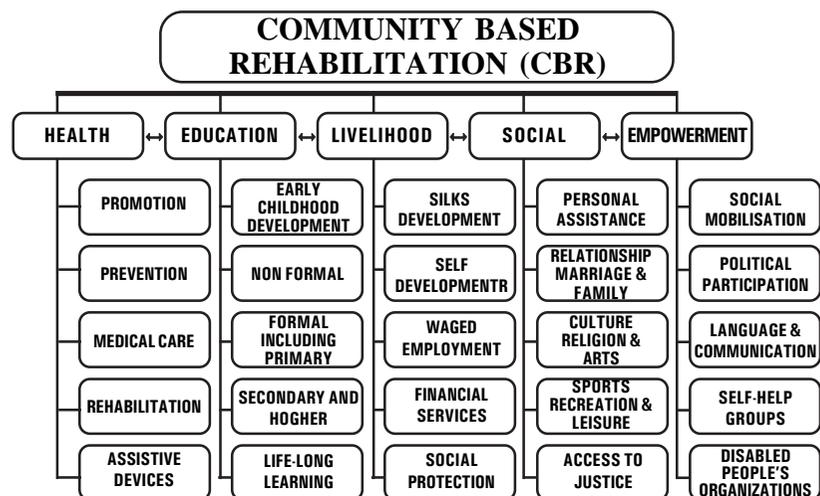
CONTENT OF THE CBR GUIDELINES

The CBR Guidelines are constructed around the CBR matrix. Each of the components has a dedicated section and each of the elements has a dedicated chapter in the Guidelines. Each component begins with a preamble which introduces the component as well as the elements which form the component. For example, the livelihood component of the Guidelines has a preamble and five elements in the CBR matrix. Additional chapters are designed to provide further background (the introductory chapters), provide specific information for planning and managing CBR (CBR management component) as well as highlighting particular circumstances (supplemental chapters). In addition the Guidelines have an executive summary which can be used as a stand-alone summary for policy makers.

A summary of the contents of the CBR Guidelines

INTRODUCTION	EDUCATION COMPONENT
Background and Purpose Evolution of the Disability Concept Evolution of CBR	Early Childhood DevelopmentPrimary EducationSecondary and Higher EducationNon-formal EducationLife-Long Learning
HEALTH COMPONENT	LIVELIHOOD COMPONENT
Promotion Prevention Medical Care Rehabilitation Assistive Devices	Skills development Self-employment Waged employment Financial services Social Protection

SOCIAL COMPONENT Relationships, Marriage and Family Personal Assistance Culture, Religion and Arts Leisure, Recreation & Sports Access to Justice	**MANAGEMENT OF CBR** Planning CBR Organizing and Developing Resources Leading and Implementing Operations Monitoring and Evaluation Training of CBR Personnel Starting a CBR Programme
EMPOWERMENT COMPONENT Social Mobilization Political Participation Communication and Language Self-help Groups Disabled People's Organisations	**SUPPLEMENT CHAPTERS** CBR and Crisis Situations CBR and HIV/AIDS CBR and Mental Health CBR and Leprosy

Note: Besides the five major components, the CBR Guidelines also pay attention to certain special areas that include CBR and HIV/AIDS, CBR and leprosy, CBR and Mental Health and CBR in crisis situations. The Guidelines highlight that people with leprosy related disability, who were previously not considered as part of the wider disability context, are included as members of the disability community considering that they share the same challenges and experiences.

USE OF THE CBR GUIDELINES

The CBR guidelines are not prescriptive.

They are <u>not</u>:

- guidelines designed to answer disability-specific questions

related to impairments and technical rehabilitation issues;

- a step-by-step guide to running a CBR programme (although the management component gives information on how to start and manage a CBR programme);

The Guidelines present options, a set of components and elements that practitioners can select according to local needs and programme priorities. Practitioners may choose the most useful entry point for the programme (for example areas already existing in the programme that could be developed or strengthened). From there they can build on the existing programme by adding elements in a natural progression, in accordance with the growth of capacities and competencies. This process, combined with the process of building alliances which form the CBR network, continues to develop until a coherent programme of appropriate components and elements is formed.

Each CBR programme will be specific to the local context. Furthermore, changes over time mean CBR programmes will have to adapt to a changing environment. Ideas developed in these Guidelines provide consideration for CBR implementers to move their programmes forward.

The CBR Guidelines is one book among many tools available to the CBR manager. It complements other useful tools, among them the WHO CBR manual "Training in the community for people with disabilities" which has a different audience and purpose.

Apart from books, it is also instructive to visit other programmes, meet people with different experiences and discuss the problems they faced and the solutions they found, which are rarely described in books.

Next Steps:

- Finalisation and the publication of Guidelines

- Asia Pacific Congress at Bangkok in December 2008

- CBR World Congress in 2009

- CBR Continental and Global Network

- Global/Continental resource centres

- CBR Master Trainers' Programme

Partnerships in the Development of the CBR Guidelines

ILO

UNESCO

WHO

CBM

IDA

SSI

NAD

DPI

Handicap International

AIFO

Disability Development

 Partners

150 Global Experts

List of Countries where CBR is practiced worldwide (WHO CBR Atlas 2007)

Africa	America	Asia	Europe
Algeria	Argentina	Afghanistan	Azerbaijan
Angola	Aruba	Bangladesh	Estonia
Botswana	Belize	Bhutan	Israel
Burkina Faso	Bolivia	Cambodia	Latvia
Cameroon	Brazil	China	Romania
Congo	Chile	Democratic	Russian
Cote d' Ivoire	Colombia	Republic of	Federation
Egypt	Costa Rica	Timor-Leste	Serbia and
Eritrea	Cuba	India	Montenegro
Ethiopia	Dominica	Indonesia	
Gambia	Dominican Republic	Iran	
Ghana	Ecuador	Jordan	
Kenya	El Salvador	Lao People's	
Lesotho	Guatemala	Democratic	
Liberia	Guyana	Republic	
Malawi	Honduras	Lebanon	
Mali	Jamaica	Malaysia	
Mauritania	Mexico	Maldives	
Mauritius	Nicaragua	Mongolia	
Mozambique	Panama	Myanmar	
Namibia	Paraguay	Nepal	
Niger	Peru	Pakistan	
Nigeria	Uruguay	Palestine	
Senegal	Venezuela	Papua New	
Sierra Leone		Guinea	
Somalia		Philippines	
South Africa		Sri Lanka	
Sudan		Syria	
Tanzania		Thailand	
Togo Tunisia		Viet Nam	
Uganda		Yemen	
Zambia			
Zanzibar			
Zimbabwe			

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CHAPTER 14

CBR Programmes in Africa: a Preliminary Analysis

Adewale Adeoye, Sally Hartley

SUMMARY

An essential first step for sharing information and creating an evidence base in CBR is to identify the key stakeholders involved. Once this is achieved, the various parties can be approached for data which can then be amalgamated and compared. This chapter describes how Community Based Rehabilitation Africa Network (CAN) and the WHO have collected and collated information about CBR programmes in Africa. It illustrates that even with very simple data collection tools, useful and interesting information can be collated and analysed. Such analysis is paramount to providing an evidence base for the future development of CBR programmes in Africa.

BACKGROUND

Community Based Rehabilitation (CBR) is the rehabilitation strategy recommended by the World Health Organisation (WHO) and interestingly it reflects traditional African activities, which can be traced back for many centuries in the histories of African heritage (Miles, 1994). We know that many African countries have embraced this CBR approach as a way of integrating people with disabilities into their communities and assisting them in making the most of their lives. However, until now there has not been a list of CBR programmes in Africa, so we could not answer questions such as, how many CBR programmes are there? Who is in charge of them? What kind of CBR models are they reflecting? Who is funding them? (Vanneste, 1997).

The United Nations (UN) estimate the population of Africa to be about 922 million (UN population, 2005), with the urban and rural variation put at 38.3% and 51.7% respectively. Africa currently makes up 10% of the world's population and the peoples of Africa are fragmented into several thousand different ethnic groups (UN population, 2005). This difference in ethnic group is largely due to unique distinction in language, traditions, tribes, history, way of life, geography and religion. These cultural differences can make information sharing and communication difficult. Moreover, communication is predominantly oral in nature and the dominance of the oral tradition of communication in Africa has contributed to the absence of evidence about CBR practice (CAN, 2006; Bright lights media, 2008). This has served to undermine improvement and advancement of CBR programmes in this region of the world.

THE NEED FOR AN AFRICAN CBR DIRECTORY AND INFORMATION SHARING

Seventeen years ago, Thorburn (1991) stressed the significance of information sharing. She argued that, "*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*". Three years later, the importance of information in the evaluation of CBR is corroborated by Krefting (1994), a rehabilitation researcher who stated that the collection, analysis, and interpretation of available information about the activities as well as outcomes of CBR programmes, gives insight into what the programme is doing and how this can be improved. The following year Lele (1995) also identified information sharing in CBR practice as a paramount problem in the evaluation of CBR programmes. More recently, the importance of information sharing was highlighted by Lorenzkowski (2006), who reiterates that "*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". Therefore within the frame of CBR practice, interaction amongst stakeholders involved in CBR should be encouraged. This will foster sharing of information as well as practical experiences. It will also advance better CBR practice, which will consequently improve the quality of rehabilitation services and ensure human rights of persons with disability in Africa. An example from Malawi of how information can be collected nationally can be found in Kerac (2005).

Mohales and Miles (1998) highlighted that the value and relevance of the CBR approach can also be transmitted to the community through information sharing. For example, "*CBR programmes can provide information about the Standard Rules and can increase awareness of them*" WHO (2003). In an international consultation to review CBR organised by the WHO (2003), it was concluded that emphasis on sharing of information is essential for good co-ordination of CBR programmes.

COMMUNITY BASED REHABILITATION AFRICA NETWORK (CAN) RESPONSE TO INADEQUATE INFORMATION SHARING IN CBR

Community Based Rehabilitation Africa Network (CAN) was conceived as an NGO, based on the premise that improved information and knowledge sharing by CBR stakeholders in Africa would help promote good CBR practices, which would in turn improve the quality of life of disabled people and their families. (CAN 2006). CAN has an established functional secretariat located in Kyambogo University, Uganda, supported by an executive committee from eight different African countries (presently Nigeria, Ghana, Niger, Uganda, Malawi, Angola, Kenya, and South Africa). This Non Government Organisation (NGO) facilitates information and knowledge sharing on CBR practices and makes these accessible

on the worldwide web, through publications, meetings, workshops and conferences. It also facilitates writing workshops for CBR workers of all levels and promotes many modes of communication. These include the spoken and written word, Braille and signing, as highlighted in article two of the UN Convention on Rights of Persons with Disabilities, 2006. One of the paramount initiatives of CAN is "The African CBR directory" (2006), which profiled CBR activity from 16 African countries and 206 individual programmes. At the same time, the World Health Organisation (WHO) also worked towards creating a directory of CBR programmes worldwide and has generously made the African section available to CAN for analysis. The WHO directory has information from 24 African countries and 144 programmes. These two sources of information have some overlaps but have been joined together to form one data set. This data set has been used to investigate the nature of CBR programme development in Africa.

RESULTS OF THE ANALYSIS OF BOTH DIRECTORIES

It can be seen from Table 1. that the total number of programmes listed in both directories is 280 from 25 African countries. A greater proportion of programmes are listed in CAN's directory (206 programmes from CAN, 144 programmes from the WHO with an overlap of 70 CBR programmes). It can be seen that the majority of CBR programmes are located in Southern Africa, 112 (40%) programmes, while the lowest percentage of CBR programmes is in Central Africa with 1 reported programme (0.4%). Of course this does not mean that there is only 1 CBR programme in Central Africa, but only that neither CAN nor WHO know about the others that may be there.

However, when the data are analysed according to the type of programme management, Non-government organisations (NGOs) have 100 (35.7%) programmes and government organisations 94

(33.6%) programmes. The management sources of 86 (30.7%) CBR programmes are not-known. Most of the NGO programmes can be found in West Africa (39%), but most of the Southern African CBR programmes (53.2%) are initiated and managed by the governments of their respective countries (see Table 1).

Results from the analysis also indicate that most CBR programmes in the Southern African region involve both outreach services and community development services in their activities (42.5%), while the programmes in West Africa focus more on outreach services (58.8%).

Table 1. Number, types of CBR programme management and activities in African regions

African region	Number of programmes n=280(%)	Type of programme management			Type of programme activities			
		[10] NGOs n=100 (%)	[11] Govt. n=94 (%)	[12] NK n=86 (%)	[13] OS n=68 (%)	[14] CD n=14 (%)	[15] Both n=87 (%)	[16] aNK n=111 (%)
North	13 (4.6)	0 (0.0)	7 (7.5)	6 (7.0)	0 (0.0)	0 (0.0)	6 (6.9)	7 (6.3)
Central	1 (0.4)	1 (1.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.9)
West	75 (26.8)	39 (39.0)	16 (17.0)	20 (23.3)	40 (58.8)	1 (7.1)	16 (18.4)	18 (16.2)
East	79 (28.2)	27 (27.0)	21 (22.3)	31 (36.0)	12 (17.7)	7 (50.0)	28 (32.2)	32 (28.8)
Southern	112 (40.0)	33 (33.0)	50 (53.2)	29 (33.7)	16 (23.5)	6 (42.9)	37 (42.5)	53 (47.8)

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[10] NGOs=Non Government Organisations

[11] Govt.= Government

[12] NK= Not Known

[13] OS= Outreach services

[14] CD= Community Development services

[15] Both= Both OS and CD programme activities

[16] aNK= Programme activities Not Known

The combined directory produced a list of 15 NGOs who initiated and managed 100 different CBR programmes (see Table 2), compared with 94 government initiated programmes. The Government programmes were spread over 3 different government ministries (Health, social services and disability) as illustrated in Table 2. Among the NGO initiated programmes, a greater proportion are managed by Disabled People's Organisations (DPOs) and churches (29% and 20% respectively) and are focused on all impairment groups. Six of the NGOs target a specific type of impairment group namely, Cerebral Palsy Society targets neurological impairment; Rotary International targets physical impairment; while Deaf Aids International, Salvation Army, Save the Children, Sight Savers and World Vision International all target sensory impairments.

All the government managed programmes target all impairment groups, but most are based in the ministry of social services in their respective countries (Table 2).

Table 2. List of different NGOs and government ministries, number of programmes and their targeted impairment groups

Management of CBR Organisation		Number of programme n=280	[17]Targeted impairment groups
NGOs n=100	Cerebral Palsy Society	3	Neurological impairment
	Christian Blind Mission (CBM)	11	All
	Churches	20	All
	Comic Relief	4	All
	Deaf Aids International	4	Sensory impairments
	Disabled People's Organisations (DPOs)	29	All
	Handicap International	2	All
	Leonard Cheshire	5	All
	Rotary Club	1	Physical impairment
	Salvation Army	6	Sensory impairment
	Save the Children	3	Sensory impairment
	Sight savers	5	Sensory impairment
	World Vision International	3	All
	Valley Trust	1	All
	VSO	3	All
Government ministry n=94	Health	30	All
	Social Services	43	All
	Disability	21	All
Unknown management of CBR organisations		86	18

CONCLUSIONS

Merging both WHO and CAN directories of CBR programmes has allowed us to take a first step in developing an overview of CBR practices in Africa.

From this, we can see that:

❖ NGOs play an important role in the development and management of CBR programmes in Africa, but (perhaps challenging popular belief) Local Governments play an even bigger role.

❖ Government programmes have been able to take on the conceptual strategy that CBR is for ALL impairments, more often than NGOs.

❖ Social Service Ministries lead in the number of CBR programmes they manage and not the Ministries of Health.

❖ The creation of Ministries of Disability has been one of the strategies used to meet the challenge of disability not fitting comfortably and effectively under any one existing Ministry.

❖ DPOs and churches are already significant players in managing CBR services.

❖ Southern Africa appears to have considerable numerical strength in developing CBR programmes.

❖ Information sharing through profiling CBR practices can help to develop evidence based CBR practice in the continent.

RECOMMENDATIONS

This information is helpful in knowing the location and basic origins of some of the CBR programmes in Africa, but in order to know more comprehensively what the CBR programme situation is in Africa and in order to be able to share information more effectively, the following recommendations are made.

❖ There needs to be collaboration between CBR organisations and CAN to achieve the most comprehensive database possible. To this end CBR programme leaders should register with CAN to enrich the database. They are encouraged to provide information about their CBR programmes/ organisation using the format attached, as a guide. This should be sent to info@afri-can.org

❖ Efforts should be made by CAN to canvass for information, particularly from the 30 African countries not represented in the CAN's database by linking up with contact persons in the countries, involving and getting representations from the countries in future CAN organised CBR conferences.

❖ Southern Africa CBR programmes and the stakeholders involved in them may be a good resource to other African countries trying to set up programmes.

FORMAT FOR REQUIRED INFORMATION ABOUT YOUR CBR PROGRAMME

We invite you to become a member of CAN - it is free.

All you need is an e - mail address and an interest or involvement in a CBR programme in Africa.

Please complete the survey questionnaire below and we will send you regular information and updates of can's activities.

1) Your name :

2) Name of organisation :

   a) Postal Address:..

   b) Country:...

   b) Telephone: ....

   c) E-mail address:...................................

   d) Website, if applicable: ....

3) What are the objectives of your organisation?...............

   ....

4) What are the main activities of the organisation? Please put headings only.

   ....

5) What is your position in the organisation? ....

6) What is the name of your CBR programme? ....

7) How is your programme funded? ....

   Donor support ....

   Government support ....

   NGOs ....

If other, please specify ....

8) Are you an organisation of PWDs or for PWDs?

....

9) What year did your CBR related activities start?...... ………..

....

10) What functional difficulties do the people your organisation serves have?

....

11) What group of people does your programme serves?

Early childhood ....

School Age ....

Adolescence ....

Adults..

Older people ....

12) What is the approximate population of the community that the project/programme serves?

....

13) If you are a training institution how many people have you trained in CBR in the last 12 months? ....

14) What is the coverage of the CBR programme in your country?

Districts ....

Sub counties ....

Parishes...

Villages ....

15) Where are your activities located?

Urban ....

Rural ....

Thank you for participating!

If you would like to give us more details about your programme or activity please do so on a separate page or email.

If you have any objection to CAN using this information please inform us by email on joan@afri-can.org

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CHAPTER 15

CBR National Networks

Daniel Tsengu, Joan Okune

SUMMARY

This chapter presents an agenda for forming CBR Networks in all countries in Africa. It observes that National CBR Networks are a good example of 'group advocacy' which is a strong component of CBR and also one of the strategies for promoting CBR as the most appropriate service strategy for equalisation of opportunities and empowerment of persons with disabilities in Africa. The potential role of National CBR Networks is examined, and basic guidelines on how this can be achieved are discussed. It also provides some useful hints for effective management of national networks for CBR workers.

INTRODUCTION

One of the resolutions at the 2002 CAN Conference on Community-Based Rehabilitation in Uganda was to actively encourage the formation of National Network for CBR workers in all African countries (Hartley, 2002). The participants at the conference observed that such national indigenous organizations, if well organized, could serve as a unified force, capable of influencing government policies and generally promoting and improving CBR services on the African continent.

A National CBR Network is a network for all CBR practitioners and persons interested in CBR in a given country. These are persons who share common concerns about the practice of CBR (raising standards, improving quality of service delivery etc.) and public

interest (prevention of disabilities, empowerment of PWDs etc.). They would also work together in collaboration with other stakeholders for protecting such interests. CBR national networks could eventually have clearly stated objectives, defined membership, and documented methods of operation and activities. Initially they are likely to operate less formally.

Experience suggests that resources are being made available by outside organisations to promote development and rehabilitation work in Africa, without the corresponding local initiatives to support and guide them. Because of this '...*some countries are sinking deeper and deeper into 'dependency on donors'*...and *'resources provided to programmes may not be adequate and/or some of the resources may be misused"* (Hartley, 2002). This practice is likely to provide only a temporary solution to the challenges and is one which is not sustainable. There is an urgent need for coordinated local approaches built on well organised local self-determination. These need to stimulate local initiatives and leadership as an instrument of change, coordination and sustainable development. The emergence of a National Network for CBR workers in African countries could provide the much needed local leadership to mobilise the people and government towards attainment of improved quality services for persons with disabilities.

IMPORTANCE OF NATIONAL NETWORKS OF CBR WORKERS

The success of CBR programmes often revolves around the principle of collective responsibility with emphasis on active participation of all stakeholders. This participation can be achieved by building synergies through networks of stakeholders and partnerships with other organisations. This would involve building advocacy systems, multi-sectoral collaboration and connections with professionals and other stakeholders (Finkenflugel H, 2006). This means if CBR is to achieve high quality results there is need for close coordination, collaboration and cooperation between governmental and non-governmental organisations, disability service practitioners and disabled persons' groups at all levels. National Networks for CBR workers as coordinated groups with a wide range of representation are seen as having the potential to play a very crucial role in the development of CBR services on the African continent.

Some of the specific benefits from the formation of National CBR Networks:

- Build the capacities and competencies of members through creating a forum for sharing of knowledge and skills among members.

- Help to pull together useful ideas from individual or collective experiences of members to develop what constitutes best practice in CBR.

- Participate as a group, in national and international debates regarding disability issues to inform appropriate policy formulation and redefinition of disability agenda.

- Contribute to the planning and design of some national projects to benefit persons with disabilities

- Develop practical and workable fund raising initiatives to ensure sustainability of CBR programmes and other disability services in general.

- Participate in international, national or local research activities to further the development of CBR services in specific, and disability work in general.

- Provide information to CAN and other organisations on CBR and disability issues to share with other African countries.

SUGGESTED STEPS IN THE FORMATION OF NATIONAL CBR NETWORK

Our interaction with people from different countries during the CAN conference in South Africa in 2007 revealed that while there are many networks for persons with disabilities in all African countries, National Networks of CBR workers exists only in Uganda, South Africa and Kenya. In other countries these networks were just beginning to develop. In Nigeria for example, CBR practitioners have been sensitised about the need for the formation of national networks, and they have organised a few meetings to discuss about the best way to go about it. It is hoped that this will be officially launched during the National CBR Conference coming up early in 2009. However, most of these countries reported that initiation and operation of these networks have not been successful.

In Uganda for instance, there have been several attempts to set up a CBR National Network. One of the reasons this has proved difficult is that '*no one is willing to take the responsibility and put in the resources necessary to start the fire*' (member of the CBR network in Uganda). She also observed that '*it would not be right to have CBR Africa Network (CAN), with a secretariat in Uganda, take on the lead role in formation of the network as this would not reflect well on CAN's regional role if it started playing 'mummy' for Uganda CBR National Network.*' Poverty was also cited as a hindrance since '*people are poor and doing extras in the evening to make ends meet*'. It also seems that reliance on formal procedure for the formation of a network and lack of resources to support this was a hindrance in Uganda.

In Ghana however, the reverse is the case. Sight Savers International, an organisation committed to combating blindness and restoring sight in developing countries, is supporting the set up of a CBR National Network with a bias towards a more formal arrangement. Considering this, it is important to look at two options when it comes to the formation of a CBR National Network: a formal arrangement and one that is less formal.

Questions to consider before starting such networks include:

What is the overall goal of the network?

What are the specific objectives of the network?

What will be the network's activities?

Who will be involved and how?

How will the network be effectively managed and sourced for in order to achieve the desired goal?

The answers to these questions will help a group to take the first steps towards forming a group that is contextually relevant and practical.

The steps necessary for formation of a formal National Network for CBR workers include;

1. Identifying a working group with common interest and vision. At this point, it is important to source for funds for organizing subsequent meetings. This could come from personal contributions from "founding" members or donations from friends and local NGOs with related interest.

2. Arranging for a meeting where a mission statement that describes the purpose of the network shall be discussed and stated. During this meeting, participants can brainstorm on issues regarding membership, objectives, initial finances, constitution etc. It is important that aims of networks are set in accordance with the local needs and ideas of persons concerned.

3. Organizing a general meeting of members to discuss the whole vision of the network and share suggested ideas regarding formation of the network, collectively draw out objectives, discuss more on membership and activities.

4. Organizing a second meeting for members to elect officers. This meeting could also discuss the constitution: membership, official duties, activities, finances, and other guide principles. Collectively develop a plan of action with a timetable and lines of accountability. It is also important that the constitution should conform to the government's regulations regarding formation of such networks.

5. Initiate registration of network with the government. This gives the network a legal identity and authority to operate without unnecessary restrictions.

6. Introduce your network to the public. This explains your identity and what you stand for to members of the public and government. This also provides opportunities for collaboration with other related NGOs and related networks.

Formation of a more 'informal' CBR National Network

Let us return to the example of Uganda where members, after unsuccessful attempts at a formal CBR National Network, have decided to develop a more informal CBR National "*Club*" With this members meet over drinks at an agreed venue after work once every month to share what has been going on in their CBR programmes. They also have plans for activities and topics of discussion at different meetings.

An informal arrangement like this could very well be the much needed ingredient for this group to take off. As evidence seems to suggest, a very formal approach is one of the barriers to the development of CBR National Networks. It also provides a barrier to action (i.e. a group may find itself spending all their time and money setting up and following the formalities that they do not actually do much by way of CBR sharing and learning from each others' experiences in the field).

When it comes to formation of CBR National Networks then the important thing is for each country to work with the option that best fits within their context. This could be governed by any number of factors that may vary from availability of resources to the nature of preferred work style/culture.

HINTS ON HOW TO MANAGE NATIONAL CBR NETWORKS

1. Set up a management structure. A formal management structure for each network can be made up of the president or chairperson with a secretary, treasurer and general members. The president/chairperson presides over the affairs of the network. The constitution of each network spells out the roles and responsibilities of all members of the executive committee. For effective administration, the executive committee, in consultation with the general members will sometimes appoint sub groups to oversee specific emerging projects of a network. Members of the executive committee should be committed and have passion for the vision of the network. They should have good leadership and management qualities, as well as a positive attitude.

2. Alternatively a less formal structure can be promoted without official officers and formal structure, but in this case it is still advised that the goals, objectives and activities are clearly defined

3. Whichever kind of group develops, a clear accounting system is required. It is very important that every network puts in place a reliable accounting system to ensure transparency and accountability. If and when the group becomes big and truly transnational with a considerable financial turnover, it will need an external auditor of reputable background to audit the accounts of the network.

4. Put in place a clear internal control system in management of finances of the Network. Most networks are not doing well because they do not have or adhere, to rules and procedures for administration of their finances.

5. Ensure efficient management of resources. Always explore possibilities of achieving good results at low financial cost to the network. Effective networking and collaboration with other organisations can to be very helpful in this regard.

6. Ensure that action plans of the network are strictly followed through. Every network builds its reputation on how well organised it is, as well as the quantity and quality of activities that it is performing.

7. Audit, Monitor and Evaluate. Ensure that your financial records are audited, activities monitored and carefully supervised. At a given point in time, every network should review its activities to ascertain achievements made, lessons learned and plan for future improvement.

HOW TO REGISTER YOUR ORGANIZATION WITH CAN

As a catalyst to the formation and strengthening of CBR National Networks, it is important that your national network is registered with CAN. The benefits of this include:

•   being part of a continental network ensures that you receive regular updates and information about CBR programmes in other countries

•   provides the opportunity for you to share information about your own network with other networks

•   contributing towards documentation and sharing of CBR information on the African continent with the end result of

improving practice and improving quality of life among disabled people in Africa and beyond

To promote the collection of information on CBR in different countries, CAN has suggested some activities for national networks to consider. These include:

•   Information about agencies implementing CBR in their countries. This would include a brief on the activities of these agencies, their target groups and areas of service

•   Success stories from CBR projects – these would be both really positive experiences but also the ones that are not so good so as to promote learning

•   Profiles of Organisations of Persons with Disabilities (OPDs) - this would include a brief on the activities of these agencies, their target groups and areas of service, and by whom and how they are run.

•   Profiles of professionals specialising in particular CBR areas like mental health, economic empowerment, ENT, eye care, special education, physiotherapy, speech therapy, orthopedics etc.

•   Prominent CBR documents and how to access them

•   Research papers and evaluation reports on disability programmes and how to access them, e.g., journals and publications. Information sources in and out of the country for example, resource centres, libraries, studios, websites, media houses etc.

•   Service providers - Specialist hospital departments, e.g., ENT, eye care, orthopedics, professional surgeons etc.

•   Available technical support resources like manufacturers of orthopedic appliances, assistive devices, equipment for the blind, educational materials etc.

- Types of CBR programmes, e.g., home based care programmes, outreach programmes etc.

- Information on history of CBR, i.e., people recognised as instrumental in CBR in your country from the very beginning

- Listings of training institutions in CBR at all levels of training i.e., Certificate, Diploma, Bachelors' and Masters' Degrees

- Information about International Development Agencies supporting CBR in your country

- List of programmes involved in advocacy and lobbying in your country. If possible, enumerate achievements made as result of advocacy activities.

- Disability events in your country and also international disability calendar, history of these events e.g., White Cane Day, Epilepsy Day, International Disability Day etc.

- UN General Assemblies-passed resolutions that you are aware of and how to access information on these. How many of these resolutions have been adopted by your country.

- Specialised schools for children with disabilities in the country, units for the blind, deaf, deaf/blind, vocational training institutions, sheltered workshops etc.

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APPENDIX 1

List of Participants

Names/Country	Contact Address
Afghanistan	
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Angola	
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APPENDIX 2.

Group Discussion Questions

During the conference, time was set aside for group discussions based on the on-going presentations. The 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, 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 could be published for wider circulation. They could be used to address issues around services, rights, research, as well as focusing on participation in CBR and how this can be achieved. We hope that our readers will find them useful.

UN CONVENTION AND CBR

1. What does the UN Convention on PWDs offer for CBR?

2. What can CBR agencies do to speed up ratification and implementation of UN Convention by different countries?

3. What do you envisage to be the likely challenges to this process in your country?

4. Is there need for harmonisation between CBR policies and the UN Convention?

DPOS' ROLE IN CBR POLICY DEVELOPMENT AND IMPLEMENTATION

1. What are DPOs in your country doing to influence policy development and implementation in CBR?

2. Can you identify any other roles that could be performed by DPOs in doing this?

3. What challenges do they face in doing this?

4. How can those challenges be overcome?

CBR JOINT POSITION STATEMENT

1. The Joint Position Statement is an important tool for guiding the implementation of CBR. How does it support implementation of CBR in your country?

2. Are there gaps in the position paper and if so, what are these gaps?

3. How can these gaps be addressed so that the position paper addresses CBR holistically?

NGO/GOVERNMENT AND DEVELOPMENT PARTNERS (TECHNICAL AND FUNDING ORGANISATION)

1. How can CBR be mainstreamed in the development programmes of these sectors?

2. What fundamental/cross cutting issues should be addressed in a CBR policy at national level and at NGO/Development partner level?

3. How can we ensure that these sectors allocate more resources to CBR?

COMMUNITIES AND CBR

1. How can CBR be enhanced to benefit the community?

2. How can the community and CBR benefit from each other?

CBR COUNTRY NETWORKS

1. What will be the role of the National CBR Network?

2. What has hindered the development of these networks?

3. Propose ways for fast tracking the CBR National Networks

ECONOMIC EMPOWERMENT AND CBR

1. How has CBR attempted to address poverty among PWDs and their families?

2. How can CBR be used as a strategy to link PWDs and their families to poverty eradication programmes?

3. What are the challenges you envisage in this?

4. How can these challenges be overcome?

UNIVERSAL PRIMARY EDUCATION AND CBR

1. How can CBR promote inclusive education with respect to UPE?

2. What challenges do you envisage to achieving this?

3. How can these challenges be overcome?

GENDER AND CBR

1. What are the key gender issues that have to be considered when developing and implementing CBR programmes?

2. How can CBR promote gender equality?

3. How can we improve gender awareness among CBR workers?

CBR AND FAMILIES IN CRISIS (BROKEN HOMES, CHILD-HEADED FAMILIES, SINGLE PARENTS, FAMILIES AFFECTED AND INFECTED BY HIV/AIDS, ETC.)

1. What challenges does the situation present to CBR workers/ programmes?

2. What strategies can CBR workers use to work with families in crisis?

3. How can CBR help families in crisis?

DISASTER AND EMERGENCY

1. What challenges do disaster and emergency present to CBR workers?

2. What are key issues that a CBR programme needs to address during a disaster and emergency situation?

3. What special skills do CBR workers need to work in this situation?

4. How can CBR be mainstreamed in programmes of agencies working in disaster and emergencies?

CBR AND GLOBAL PARTNERSHIPS

1. What threats and opportunities does globalisation present to CBR?

2. What are the key areas for North/South collaboration?

3. How can we promote documentation and sharing of experiences among CBR workers globally?

INCLUSIVE HEALTH AND CBR

1. How can CBR be used as a strategy to address challenges faced by PWDs in accessing facility- based health services?

2. How can CBR and facility-based health service providers collaborate to improve health service provision to PWDs?

3. How can linkages between facility-based health services and CBR be established and maintained?

HIV/AIDS, MALARIA, TB PROGRAMMES AND CBR

1. What threats do the rampant HIV/AIDS, Malaria and TB present to CBR?

2. How can CBR be used to reduce PWDs' vulnerability to AIDS, TB and Malaria?

3. How can CBR be used to promote access to services for the prevention and control of HIV/AIDS, Malaria and TB?

CBR AND MULTI-SECTORAL PARTNERSHIPS

1. What are the key sectors involved?

2. How can CBR establish and utilise multi-sectoral partnerships?

3. How can multi-sectoral partnerships/networks be sustained in CBR?

SOCIAL INCLUSION

1. What role can CBR play in supporting PWDs in accessing social justice?

2. What role can CBR play in supporting PWDs in accessing personal assistance?

3. Discuss the role played by the extended family (traditional safety nets) in caring for and supporting PWDs in the community

APPENDIX 3.

Key Resolutions

Alice Nganwa, Harry Finkenflugel, Sally Hartley, ? , ?

The raporteurs met and generated key resolutions from the conference proceedings. Feedback was collected, the messages were modified and ratified at the General Assembly. Suggested objectives for monitoring the progress of CBR programmes towards implementing these resolutions are also presented below. This is not an exhaustive list and people should feel free to add or delete as they see fit. This structure will be used for an evaluation session at the next conference in 2010 for feedback and information sharing.

The key resolutions are:

1.   PARTICIPATION

DPOs and PWDs should participate in the development, implementation, and use of policies, guidelines, PRSPs and PAPs

Possible objectives:

❖   Lobby governments to include DPOs and disabled people in the development of policies and guidelines, PRSPs and PAPs

❖   Take existing documents (guidelines etc., including project development proposals) and 'write in' a disability/CBR element and present to the appropriate authority for consideration.

❖   Send representatives to meetings and discussions, that would benefit from a disability perspective

2.   MAINSTREAMING

CBR and other disability programmes should embrace the inclusive development approach and actively connect with other programmes that might be relevant for people with disabilities.

Possible objectives:

❖   Lobby governments and other organisations to develop mechanisms for including disabled children and adults in mainstream programmes.

❖   Directly approach existing programmes where it is considered possible to improve the inclusion of disabled people and work together to achieve this.

❖   Offer to examine existing programme documents and project proposals to write in a disability/CBR element into the programme, for the organisations' consideration.

❖   Review micro finance/credit and other income generating facilities to ensure access by PWDs and their families

3.   CAPACITY BUILDING

To ensure effective service delivery of the CBR strategy there is a pressing and continuous need to build capacity of PWDs and service providers.

Possible objectives:

❖   Identify which areas of capacity development for disabled people are required to achieve the other resolutions.

❖   Seek to make existing appropriate training available and accessible for disabled people and their families.

❖ Actively seek funding for and develop training programmes for disabled people relating to capacity development

❖ Have PWDs as trainers on courses for service providers, especially professional/higher education courses

4. LEARNING FROM OTHERS

To enhance the development of CBR we should take lessons from other development programmes (e.g., gender, small business schemes, HIV/AIDS programmes), take their strong points and avoid their failures.

Possible objectives

❖ Implementers of CBR should investigate and take note of lessons from other community development projects through joint meetings, sharing and discussion of reports and documentation.

❖ Identify and copy the strong points.

❖ Identify and avoid their weak points.

❖ CAN/CBR association and CBR should take a lead in this.

5. BUILDING ALLIANCES

Building alliances and networks at all levels is a key element in the CBR strategy. It is stressed that creating networks at local level is most essential to the success of any CBR programme.

Possible objectives

❖ National CBR associations to identify and contact useful partners.

❖ CBR workers at all levels should build safe networks with line politicians in order to mobilise resources and promote a

positive policy environment

❖ Where Government participation or leadership is weak, CBR programmes should actively seek to strengthen the link and role of Government in the programme.

6. RESEARCH

In order to add to the evidence base of CBR, ethically robust research studies should be set up within and alongside CBR programmes to describe good practices, identify indicators, and develop instruments to assess the quality of CBR programmes.

Possible objectives

❖ Organizations working with/in CBR programmes should establish/strengthen base line information and monitoring strategies for CBR programmes and disability related activities.

❖ Share this information with and through CAN.

❖ Secure resources to carry out research whenever possible, e.g., write a research element into project proposals, including hiring of research staff.

❖ CAN should help link CBR programmes to researchers to provide support and training.