Community Based Rehabilitation for Resilience Building and Sustainable Development: *Leave No one Behind*

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Foreword

It is a great honour for me to write the foreword to this book which recollects the highlights of the 6th CBR Africa Network Conference. The conference was held at Intercontinental Hotel, Lusaka, Zambia from 7th – 11th May, 2018 with the theme*:* ***"CBR for Resilience Building and Sustainable Development: Leave No One Behind."***

This conference like all the others was organized by CBR Africa Network (CAN) to bring together stakeholders from Africa and beyond share the knowledge and ideas on disability, rehabilitation and inclusive development. The ultimate goal for this is to improve service delivery for persons with disabilities, promote their participation and inclusion.

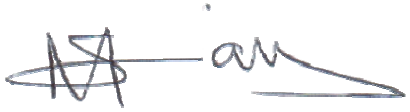
The 6th CBR Africa conference brought together 542 participants from 45 countries. Participants included male and female persons with different disabilities, service providers, disability advocates, policy makers, government representatives, political representatives at different levels in various countries and academia. This provided an opportunity for information sharing and networking which I believe will have a great contribution to the Sustainable development Goals which are determined to leave no one behind.

The conference was particularly honoured by the attendance of the Republican President of Zambia, Mr. Edgar C. Lungu and First Lady Madam Esther Lungu, an indication of government commitment to ensure disability inclusion. For CAN, this put the CBR Africa Network Conferences in a different league and places greater demand for higher commitment from host governments of countries wanting to host the event including significant financial support and high level attendance!

The book highlights what was shared at the conference which included thoughts about CBR and CBID, education and training in CBR and disability generally, early childhood development, disaster management and self-help groups for economic empowerment and collective action by persons with disabilities.

I hope that this book will be of great benefit and be a reminder of what transpired. You are further encouraged to continue sharing your knowledge and ideas through the CAN network for the benefit of all people working in this sector. Kindly identify your CAN Country representative and participate in all CBR/CBID related activities within your country and thereby in the region.

Happy reading!!



Musonda Siame
Chairman CAN Executive Committee

Zambia Federation of Disability Organisations – ZAFOD

It was indeed a great privileged for Zambia to host the 6th CBR Africa Conference in May 2018 in Lusaka. We warmly welcomed more than 400 delegates, both local and international to the first ever disability conference to be hosted by Zambia at global level. Zambia's participation in previous conference has been notable, which led to identification of the Chairman of CBR Africa Network at the time. Zambia is a signatory to the UNCRPD (2006), which was ratified in February 2010 and has since been domesticated under the Persons with Disabilities Act of 2012, guaranteeing the rights of all persons with disabilities.

A study commissioned by the Zambian government with funding from UNICEF in 2015 estimated overall national disability prevalence of 7.7%, with the prevalence among those 18 years and above at 10.9% percent. Prior to hosting the Conference, Zambia welcomed the UN Special Rapporteur on disability in year 2016, whose findings and recommendations helped inform and inspire the country to host the forum. In addition, the Zambian government demonstrated commitment by depositing its first post UNCRPD ratification report in September 2017, paving the way for the organizations of person with disabilities led by ZAFOD.

We felt honored when the president and first lady officiated the event in Lusaka. It made it clear to the country and the world that Zambia is committed to disability inclusive development. Building on the successful hosting of the CBR Africa Network, government is working with other stakeholders to fulfil its several commitments among which are inclusive education, economic empowerment, provision of assistive technologies, improved disability inclusive data collection, elimination of discrimination against persons with disabilities, accessible information and infrastructure and effective service delivery as well as prioritizing girls and women's with disabilities and mainstreaming efforts for inclusive development.

The CBR Africa conference will go down in history and be remembered for promoting the full participation of children, young people and other marginalised disabilities. ZAFOD and the entire disability fraternity in Zambia looks forward to the next CBR Africa conference in another host African country and the upcoming 3rd CBR/CBID World Congress to be held in Africa.

Long live all disability advocates in Zambia and world over. Long live Zambia.

One Zambia, One Nation!

EDITORIAL

Carolyne Maholo Sserunkuma, Victor Locoro, Moses Ddamulira

INTRODUCTION

This book is an output of information sharing at the sixth conference organized by the CBR Africa Network (CAN). CBR Africa conferences are attended by stakeholders in disability, rehabilitation and inclusive development. With the aim of promoting information sharing to generate lessons for improved service delivery. The contents of this book have been developed from conference presentations, discussions and lessons obtained at the sixth CBR conference held in Lusaka, Zambia in 2018. In this book, some chapters reflect presentations made at the conference while others have been reinforced with additional information from discussions, fieldwork experiences from different parts of Africa and relevant literature.

Considering the various changes experienced in the world since the declaration of the sustainable goals in 2015, the conference was held with the theme *"CBR for Resilience building and Sustainable Development: Leave no one behind".* It provided an opportunity for participants to explore the various developments in CBR and disability inclusive development.

WHAT THIS BOOK OFFERS

This is a reflective piece of work that can be used as a basis for future action throughout the African continent and other similar contexts. The contents not only provide an overview of present day CBR knowledge, but show how this information has been interpreted and implemented in the African context. The writers are predominantly of African origin and they ably provide an insightful view of the dynamic nature of CBR and its capacity to respond to contextually different challenges. They provide examples of their own CBR experiences and case studies of their programmes, the problems they face and how they were overcome. This is therefore another positive step in the journey of African people to share their own experiences and develop their own solutions to their problems within the context of their own cultural perspectives.

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

WHAT THIS BOOK CANNOT OFFER

This book is not intended to be a manual on implementing CBR and therefore cannot be used as such. It does not provide a 'best' way of developing CBR programmes, but gives a description of what different people have done, in different countries and different contexts to empower persons with different

disabilities and overcome the barriers presented to them. It examines what appears to have worked and why, and what has not worked and why, in a variety of locations. In this edition, most of the chapters are more descriptive by nature and differ in style and presentation. The book intentionally gives room to a diversity of styles and points of view, as a way to stimulate the debate and nurture reflections around CBR and CBID. Therefore, the contents and opinions presented in the various chapters do not necessarily account for, nor represent the views of the editors.

WHAT ARE THE KEY MESSAGES OF THIS BOOK?

Chapter 1 (*Transitioning from Community Based Rehabilitation to Community Based Inclusive Development: A Discussion at the 6th CBR Africa Conference)*explores the recent debate on transitioning from CBR to CBID highlighting the key aspects in each concept to inform deliberation by stakeholders.

Chapter 2*(Identification of Essential Standards for CBR/CBID Fieldworker training in Disability Inclusion)*is based on a study undertaken in Africa and Asia to identify essential standards for CBR/CBID fieldworkers. It highlights capacity gaps and provides recommendations for effective skills development and competence building of CBR/CBID fieldworkers.

Chapter 3*(Early Childhood Development and Disability)* in line with SDG4, this chapter highlights experiences in ECD and the contribution of CBR/CBID to ECD for children with different disabilities.

Chapter 4 *(CBR/CBID Training in Africa for Resilience and Inclusive Development)* recognizing the continuous need for capacity development at different levels to empower persons with disabilities, this chapter highlights CBR/CBID training by different stakeholders in Africa in different contexts.

Chapter 5*(Village Savings and Loan Associations: An Empowerment Opportunity for Persons with Disabilities)* financial exclusion of marginalized individuals such as persons with disabilities has given rise to indigenous community-based solutions for collective saving and loan access. This chapter highlights experiences of VSLAs in different parts of Africa contributing to economic development.

Chapter 6 *(Self-Help Groups for Mobilizing Caregivers of Children with Disabilities in Kenya and Cameroon)* with an example of two projects, this chapter presents the contribution of self-help groups to improving the lives of persons with disabilities at different levels.

Chapter 7 *(Community Based Rehabilitation and Disability Inclusive Disaster Management)* recognizing the vulnerability of persons with disabilities in disaster situations, this chapter presents their plight and the relevance of CBR/CBID in disability inclusive disaster management.

Chapter 8 Key resolutions from the 6th CBR Africa Network Conference were formulated and endorsed by conference delegates composed of representatives of various governments, organizations and institutions. The 13

key resolutions prompt readers to examine their own CBR activities against what the conference participants collectively recommended, to enhance service provision to persons with disabilities, promote their participation and inclusion at all levels.

WHO SHOULD READ THIS BOOK?

All people interested in the community-based programing and disability inclusion will find this book useful and interesting to read. Our hope is that all lessons and ideas shared contribute to service provision and help caregivers to effectively meet the multiple needs of persons with disabilities at individual, family and community level.

Chapter 1

Transitioning from Community Based Rehabilitation to Community Based Inclusive Development: A Discussion at the 6th CBR Africa Conference

SoumanaZamo, Abdul Busuulwa, Moses Ddamulira

Introduction

The Community-Based Rehabilitation (CBR) approach reached the mark of exactly forty years in 2018. Over the four decades, CBR has made a significant contribution to the wellbeing of persons with disabilities and their families in developing countries (WHO, 2010). CBR has not only enhanced access to diverse social, economic, medical and rehabilitation services but has also empowered persons with disabilities and prompted their human rights.

Since the launch of the Sustainable Development Goals (SDGs) by the United Nations (UN) in 2015, there has been increased debate among some disability stakeholders about the need to transition from CBR to Community Based Inclusive Development (CBID). Proponents of CBR argue that in its current form, CBR is still a viable and effective strategy for meeting needs of persons with disabilities and facilitating their participation and inclusion in society (ILO, WHO, UNESCO, 2004; Finkenflugel, 2004). On the other hand, advocates of CBID contend that CBR has played its role and that now is the time to transition to CBID. The proponents of CBID argue that it is cost effective and sustainable to address the needs of persons with disabilities alongside those of other vulnerable populations.

In Asia, Latin America and Africa, many disability and development stakeholders continue to implement CBR projects and programs while others have rebranded their activities as CBID. There are also stakeholders who seem to be undecided which way to go and opt to refer to their activities as CBR/CBID. The 6th CBR Africa conference that was held in Lusaka – Zambia in May 2018, provided an opportunity for stakeholders to further debate on CBR and CBID.

Two workshops were held concurrently. One of the workshops examined the current CBR practice and its challenges while the other workshop centered on the CBID concept, justifications and prospects. The summary of the discussions in the two workshops were presented to the plenary. This chapter highlights proceedings of the two workshops and the plenary.

Workshop 1: The CBR Concept and Practice

Participants

The workshop drew a cross-section of participants including persons with disabilities, parents, community development officers, CBR practitioners, project officers, government officials and academia.

The CBR Concept

Participants of this workshop viewed CBR as a strategy for promoting access to rehabilitation services for persons with disabilities and for enhancing their participation and inclusion in society. They noted that since 1978, CBR has gone through different positive milestones: Perspectives of disability have changed; principles and techniques relating to interventions have been developed; research and documentation on disability and CBR has been enhanced; human resources have been trained at different levels; in many countries disability friendly laws and policies have been put in place. CBR was further credited by participants for its contribution to increased human rights awareness, poverty reduction and advocacy for disability inclusion. Currently CBR has guidelines for practice and its ultimate goal is disability inclusive development.

The CBR Practice

Participants noted that CBR has been adopted by some countries in Asia, Pacific, Latin America and Africa as the official strategy for meeting needs of persons with disabilities and their families. CBR is also being implemented by local, national and international stakeholders through different projects and programs. Many projects and programs focus on different components and elements of CBR. While some of these target children, women or specific disability groups with individual centered rehabilitation services, others focus on broader issues such as advocacy, capacity building and economic empowerment.

In a bid to ensure holistic intervention, CBR recommends the use of a twin-track approach to service delivery. This involves application of interventions to meet specific needs of persons with disabilities and their families as well as addressing barriers to participation of persons with disabilities in the community.

In many countries, CBR projects and programs are government funded while others depend on donors. The human resources for CBR vary. They include volunteers, personnel with informal CBR training, those with formal CBR training at different levels, health professionals, community development workers and teachers among others.

Lessons Learnt while Implementing CBR

1. CBR projects and programs should be informed by a baseline study and periodic assessment to ascertain needs and keep abreast of strengths, weaknesses, opportunities and threats. This not only maintains relevance of projects and programs but also contributes to sustainability.

2. CBR has proved to be a cost effective strategy for working with persons with disabilities and their families. This is partly attributed to its nature - being community based, deeply involving persons with disabilities and their families and using locally available resources.

3. CBR programs that have been in existence for long, started small and gradually expanded in scope and range of services. This gradual growth process allows programs and stakeholders to learn from their experiences and to gradually scale up best practices.

4. Many CBR projects and programs encounter funding challenges. They lack reliable sources of funding and hardly generate own finances. Those benefiting from government support also reported funding inadequacies due to among others competing priorities on the part of government. Shortage of funds compromises provision of services, coverage and sustainability of interventions.

5. CBR stakeholders have varying capacities and resources. Networking, collaboration and building alliances is crucial as it enables effective CBR implementation through sharing information, experiences and resources. In addition, when CBR actors ally, they are in a better position to influence and impact duty bearers such as government and providers of various services. For example, in some countries, CBR stakeholders have successfully worked together to influence government to review existing laws and policies for disability inclusion and to enact new ones. Also in some countries, CBR stakeholders including organizations of persons with disabilities have been instrumental in advocating for disability inclusive planning and budgeting at different levels as well as establishment of key institutions that support persons with disabilities.

6. For effective programming of CBR, it is necessary to have a conducive legal, policy and institutional framework. Participants observed that many countries in Africa, Asia and Latin America have disability friendly laws and policies. However, the implementation of these laws and policies remains a challenge. In addition, it was noted that many governments have established ministries, commissions, agencies and departments to contribute to rehabilitation and disability mainstreaming. Even then, these institutions were reported to be grappling with challenges relating to financial, human and other resources.

7. Political will at different levels of governance was identified as a key ingredient for the effective implementation of CBR. This enables prioritization of disability in planning, resource allocation and programming.

8. Depending on the model being pursued by a CBR project or program, personnel with different competencies are essential. Such skill-mix enriches the rehabilitation experience and contributes to holistic intervention. For effective implementation, CBR workers ought to have positive attitude towards persons with disabilities and their families, empathy, passion, commitment and willingness to learn. Other qualities cited include flexibility, patience, selflessness, effective resource mobilization and utilization. Given the dynamics relating to needs of persons with disabilities, the CBR strategy and the environment in which projects and programs operate, there is need for continuous capacity development of CBR personnel.

Challenges to CBR Implementation

Participants identified several challenges to CBR implementation:

- Limited data on disability and persons with disabilities. This limits effective advocacy, planning, budgeting and programming.
- In developing countries, a strong relationship between disability and poverty still exists. This not only exacerbates effects of disability but also undermines capacity of persons with disabilities and their families to engage in social and economic ventures.
- For a number of reasons, prevalence of disability is on the increase throughout the developing world yet this is not matched with relevant rehabilitation services.
- In spite of the contribution made by CBR and stakeholders in nurturing positive values, attitudes and practices among populations, there is still widespread exclusion of persons with disabilities and their families in government and civil society service provision and development processes.
- Negative attitudes towards and among persons with disabilities still exist which curtail progress toward an inclusive society.
- Limited or lack of representation of persons with disabilities in key decision making structures of governments and civil society in many countries denies persons with disabilities opportunity to articulate their concerns.
- Although laws and policies on disability exist in many developing countries, these are often not implemented.
- Limited or lack of awareness of existing laws, policies and programs by persons with disabilities and their families limits their involvement and capacity to advocate for their rights, participate in decision-making and hold stakeholders accountable.

- In many countries, participation of persons with disabilities is still undermined by a multitude of barriers.

Despite the above challenges to CBR implementation, participants agreed that CBR with its mission, principles and practices, is still a relevant, effective and viable vehicle for promoting rehabilitation, inclusion, equalization of opportunities, socio-economic empowerment and improved quality of life for persons with disabilities and their families in developing countries.

The above were identified by participants of the workshop as challenges to CBR implementation. It is obvious that individual countries, programs and projects have distinct challenges.

"What is the situation like in your setting?"

Workshop 2: The CBID Concept and Practice

Participants

The workshop was attended by persons with disabilities, parents, and community development officers, representatives from organizations of persons with disabilities, CBID practitioners, project officers, government officials and politicians.

The CBID Concept

Participants noted that CBID was a new concept which emerged around the time of the launch of the Sustainable Development Goals but some admitted that they did not know much about it. A presentation made by the lead facilitator of the workshop clarified that:

CBID is a community-based approach that improves the lives of persons with disabilities by working with and through local groups and institutions to ensure that persons with disabilities are respected and included in all areas of life. It is an approach that creates an environment where communities become more inclusive, resilient and participatory. CBID is a people centered, community driven and human rights-based approach that practically addresses the challenges experienced by persons with disabilities, their families and communities.

CBID is based on the following principles: Social justice, self-determination, participation, learning and reflection as illustrated below:

Figure 1: CBID Principles

Adapted from Asia-Pacific Development Center on Disability

The CBID Practice

Participants noted that:

- CBID is still in its infancy.
- Some projects and programs in Africa have embraced CBID.
- CBID projects and programs are largely donor funded; governments are yet to adopt this approach.
- Because it is fairly new, CBID uses personnel with the CBR and community development orientation.
- In Africa, there are yet no formal training opportunities on CBID. Informal trainings are organized for stakeholders at project and program level.
- Literature on CBID is scanty. Practitioners still use CBR reference materials.
- CBID contributes to inclusiveness, resilience and participation, equalization of opportunities for all vulnerable populations including persons with disabilities and is deemed good for poverty reduction.

Challenges to Implementation of CBID

Participants identified some challenges to CBID implementation:

- Limited awareness on CBID.
- Limited data on disability.
- Widespread exclusion and discrimination of persons with disabilities still exists.
- Limited space and opportunities for persons with disabilities to participate in making choices and decisions about what concerns them.
- Many persons with disabilities still have limited access to opportunities for health, rehabilitation, education and training as well as livelihood development.

Why transition to CBID?

Workshop 2 contended that CBID relates to inclusive development. Inclusive development is a global aspiration that calls for all stakeholders to be cognisant and responsive to needs of vulnerable populations including persons with disabilities. The assumption is that promoting CBID will ensure that concerns of persons with disabilities and stakeholders are considered together with those of other vulnerable populations and are treated as an integral part of mainstream planning and implementation. This will in turn ensure that development stakeholders, services and support systems at all levels are disability sensitive and responsive to needs and human rights of persons with disabilities over and above their regular focus with vulnerable populations.

Transitioning to CBID will further facilitate networking and collaboration to optimize resource mobilization and utilization. All these will ensure that initiatives aiming at empowering vulnerable persons including persons with disabilities and their families are sustained and that no one is left behind in development processes.

The Plenary

Reports from the CBR and CBID workshops were presented at the conference plenary for wider dissemination. For CBR, participants observed that:

- CBR as a strategy is widely known by stakeholders.
- In many countries, CBR has proved to be effective in responding to needs of persons with disabilities and their families.
- The twin- track approach to interventions is quite useful.
- CBR advocates for the use of local resources in rehabilitation for cost effectiveness. However, this quest is undermined by poverty and limited knowledge and skills on mobilization and use of available resources in rehabilitation.

- CBR has continued to utilize services of volunteers. Many projects and programs encounter difficulties in sustaining voluntarism.
- Many CBR initiatives experience challenges associated with sustainability. In spite of these challenges, CBR is still a reliable and viable strategy.

Regarding CBID, participants noted that:

- CBID appears to be a goal rather than a strategy.
- CBID shares the same principles and techniques with CBR.
- Where CBID has been adopted, it is largely due to donor conditionality.
- In its current form, CBID is too generalist. It advocates for needs of persons with disabilities to be addressed alongside those of other vulnerable populations. This may render disability specific concerns submerged.
- CBID has not been implemented long enough for stakeholders to draw lessons and to assess its practicability, effectiveness and relevance.

Conclusion

CBR and CBID aim at improving wellbeing of persons with disabilities and their families although they seem to differ on how to realize this. One may even argue that it is an issue of nomenclature. Apparently, projects and programs that have adopted CBID continue to implement similar interventions they had under CBR. They also employ the same approaches as before. What has changed or what is being done differently is not clear. CBID is young and has not yielded many lessons, so it would be too early to judge it now. CBID should be given a chance to thrive and stand the test of time. On the other hand, CBR is quite familiar, has been implemented for long, has generated lessons and proven to be a viable strategy for empowering and enabling persons with disabilities and their families. In light of this, each project or program is encouraged to choose whether to consolidate work as CBR or to consider transitioning to CBID.

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Chapter 2

Identification of Essential Standards for CBR/CBID Fieldworker training in Disability Inclusion

HuibCornielje, ElieBagbila, Victor Locoro

Introduction

This chapter details a study that was undertaken by Enablement, the Liliane Foundation, Light for the World International, and the International Federation for Spina Bifida and Hydrocephalus (IFSBH), Caritas Germany, the Norwegian Association of the Disabled (NAD), Mission East and the Vietnam Assistance for the Handicapped (VNAH) in 2017 in six countries namely Burkina Faso, Malawi, Zambia, Uganda, Tajikistan and Vietnam. The qualitative study targeted 15 organisations, some governmental and others non-governmental, allimplementing several CBR/CBID programmes. The study focused on identifying essential standards for CBR fieldworkers' training by exploring profiles of field workers, training conditions, and support systems in different contexts. The chapter gives an overview of CBR/CBID, highlights the objectives of the study, methods employed, and findings and provides recommendations for effective skills development and competence building of CBR/CBID fieldworkers.

CBR and CBID: An Overview

CBR was initiated in 1976 by the WHO with the aim of contributing to *"Health for All by the year 2000"*. In 1978, CBR was embraced by the Alma-Atta Conference as a cost-effective method for service delivery and promoting access to rehabilitation services for persons with disabilities especially in poor resource settings. Whereas the initial understanding of CBR by the WHO in 1978 was medically and individually oriented, CBR later evolved into a multi-sectoral strategy addressing broader eco-social realities of persons with disabilities. During this development, WHO, ILO and UNESCO widened the scope of CBR to encompass issues relating to community development, social integration and equalisation of opportunities for persons with disabilities. In addition, attention was given to human rights, poverty reduction, inclusive communities and the role of Organizations of persons with Disabilities (OPDs). Thus in 2004, CBR was redefined as "A strategy within general community development for the rehabilitation, poverty reduction, equalisation of opportunities and social inclusion of persons with disabilities." (Iemmi et al, 2015; Khasnabis et al., 2010).

As CBR was being redefined, the process of developing the CBR guidelines and UN Convention on the Rights of Persons with Disabilities (UNCRPD) started. The CBR guidelines were launched in 2010 with a goal of Inclusive Development. This further contributed to the shift of CBR from being merely a service to being human rights-based approach.

Using the principles of participation and inclusion, many CBR programmes became more involved in inclusive development work at community level. CBR initiatives continually address individual needs of people with disabilities and their families on one hand and promote disability-inclusive development at community level on the other hand.

After the launch of the CBR guidelines, more and more projects began – largely initiated by INGOs - to associate with the CBID approach arguing that it is a better vehicle for advancing participation and inclusion for all marginalised populations. However, some practitioners have observed that CBID does not put much emphasis on rehabilitation service delivery but rather concentrates on advancing the community mobilisation model. CBID initiatives have also been criticized for investing more in training field staff in disability rights, networking and advocacy leaving a capacity gap in meeting the individual needs of persons with disabilities and their families. Nevertheless, many programmes and projects worldwide continue to use the CBR strategy for disability inclusion.

The Case for Essential Standards in CBR/CBID Training

CBR/CBID is implemented through the combined efforts of different stakeholders. Essential in every CBR/CBID programme, are field workers who provide services to and promote participation and inclusion of persons with disability, their families and the community (Mannan et al, 2013; Rule, 2013). In 1989, Helander et al. developed a series of manuals for training field workers these manuals provided technical rehabilitation skills for different people with disabilities and their caregivers and were based on the way disability was understood then. Despite the shift in perspectives of disability and CBR over the years, these technical manuals have not been updated to be in tandem with current trends. For example, although still relevant the manuals do not address important issues of social justice, equity, socio-economic inclusion, accessibility and participation among others. Also, these manuals do not represent a broader focus of CBR covering interventions in other life domains such as education, health, livelihood, social and empowerment. Although the manuals have a lot of content on activities for individual rehabilitation, they lack guidance on training methodology, training assessment and expected outcomes of training (Rule, 2008). CBR/CBID programmes that still train field workers based on these manuals are likely to limit their focus on improving functioning of the individual with a disability (e.g. providing exercises, medicine, training to do various tasks and providing assistive devices) without

emphasizing addressing accessibility barriers and promoting rights of persons with disabilities (Iemmi et al, 2015).

Whereas the CBR Guidelines provide a rich theoretical and philosophical framework for CBR, they also do not offer clarity on essential standards for training of CBR field workers. Indeed, O'Dowd et al (2015) identified a shortage of field workers with appropriate CBR skills which undermines comprehensive access to CBR/CBID services. However, literature provides some suggestions on what perhaps CBR field workers require: a complex skill mix; to be multi-skilled rather than profession-specific; skills on overcoming social oppression of people with disabilities; skills in community development, advocacy and to learn techniques to empower people with disabilities (Maclachlan et al, 2011; Rule, 2008).

Many CBR programmes and development organisations do not have a shared idea about roles and tasks expected of a field worker and literature hardly addresses the topic (Mannan et al, 2013; O'Dowd et al, 2015; Rule, 2013; Wirz, 2000). Although there is some common understanding - at least in theory - on the content of field worker training, there is considerable variation in terms of duration of the training, level and title of persons trained, entry requirements, type of trainers, accreditation, to name but a few variables. It becomes clear that there is no uniformity in the training of field workers, their profile, roles and tasks (O'Dowd et al, 2015). There is a strong need to assess and improve the training packages of CBR field staff with details on selection of the field staff in relation to their role and contribution, training methodology, types of trainers, training duration and outcomes (Cancedda et al, 2015; Deepak et al, 2014; Kuipers & Cornielje, 2013; Rule, 2013). While seeking the commonality between those training packages, the variety of contexts should be put into consideration (Rule, 2008). On the other hand, Kendall et al (2000) are sceptical of the consequences of broadening the curriculum of CBR field workers. They argue that this may congest training and overwhelm trainees.

In view of the above, in 2017 partners including Enablement, the Liliane Foundation, Light for the World International, the International Federation for Spina Bifida and Hydrocephalus (IFSBH), Caritas Germany, the Norwegian Association of the Disabled (NAD), Mission East and Vietnam Assistance for the Handicapped (VNAH) embarked on an empirical study in six (6) countries in Africa and Asia. The study sought to profile existing CBR worker training programmes with a view of developing guidelines for essential training of CBR field workers. These would facilitate efforts to standardise field worker training curriculum and support systems.

The Scope

Rule (2013) identifies macro-level (national and international), organisational level, training and the profile of the student or field worker as the key components of a curriculum framework for mid-level CBR training. However,

this study focused on profile, training and organisation of CBR field worker training to establish variations in different programmes and contexts.

Study Design
Qualitative data collection and analysis methods were used. This enabled collection of in-depth information from the study participants.

Selection of Countries and Programmes
Countries and programmes that participated in the study were as in table 1 below:

Table 1: Selected Countries and programmes

Country	Partner 1	Partner 2
Tajikistan	Caritas Germany	Mission East
Vietnam	Caritas Germany	Vietnam Assistance for the Handicapped
Burkina Faso	Light for the World	Light for the World
Uganda	Liliane Foundation	International Federation for Spina Bifida and Hydrocephalus
Zambia	Liliane Foundation	Norwegian Association of the Disabled
Malawi	Norwegian Association of the Disabled	-

Selection of Countries
Six countries were purposively selected for the study- four from Africa and two from Asia. The countries were selected because partners had ongoing CBR/CBID programmes.

Selection of Programmes
Fifteen (15) programmes were purposively sampled. Inclusion criteria for CBR programmes were as follows:

- Programmes addressing more than one CBR domain (health, education, social, livelihood, empowerment)
- Programmes working with paid staff and/or unpaid field workers
- Government supported or non-government supported programmes
- Programmes working with trained and untrained field staff

This selection provided room for comparison and understanding of dynamics surrounding training of CBR/CBID field workers.

Sampling of field workers
The study employed the conceptualisation of a field worker as stated by Rule (Rule, 2008). “Field worker” is a general term that refers to the person(s) doing

the day-to-day field work and who is in direct contact with the beneficiaries. Field workers may also be referred to as "Health Extension Workers", "Community Rehabilitation Facilitators", "Community Rehabilitation Workers", or Social Workers. Table 2 below shows basic demographic data of the sample of fieldworkers who participated in this study.

Table 2: Demographic data of fieldworkers participating in this study

Country	Females % (programme)	Females # (interviews)	Males # (interviews)	Age (range)	Age (median)	With disability %	Years of Experience (range)	Years of Experience (median)	Years of education (range)	Years of education (median)
Uganda	57%	3	3	23-57	34	17%	1-20	8,5	14-18	16
Burkina Faso	26%	2	4	28-46	36,5	17%	4-22	7	7-10	7
Vietnam	71%	5	2	30-60	50	0%	3-17	12,5	12-15	14
Tajikistan	93%	22	1	23-71	41	9%	0,67-28	1	11-13	11
Malawi	18%	2	3	35-42	39	0%	12-15	13	8-16	12
Zambia	49%	9	2	33-65	45	0%	2-19	10,5	6-16	14
Total:	**55%**	**43**	**15**	**23-71**	**40**	**7%**	**0,67-28**	**7**	**6-18**	**12**

The inclusion criteria for field workers were:

- Having worked with a CBR programme for at least one year as field worker.
- Having trained in community work, social work, CBR, or similar field.
- Being in paid or unpaid position.
- Having regular contact with persons with disabilities.

Data Collection Methods

Data was collected using a variety of methods namely survey, interviews, focus group discussions and workshops.

a) Survey: This was carried out in each country to obtain background information on selected programmes.

b) Interviews: These were administered to field workers using semi structured interview guides to obtain detailed information on their tasks, skills, motivation, training needs and organisational support given to them. Interviews were also carried out with field worker trainers to obtain detailed information on the training curriculum, training needs, and field worker skills.

c) Focus group discussions (FGDs): FGDs were conducted using an FGD guide and participatory learning approaches with persons with disabilities and their

representatives to establish their needs and how they were being met by field workers.

d) Workshops: Three categories of workshops were held in each country.

- Introductory workshops were conducted with the study team in each country to orient the team on the field activities to be carried out.
- Field worker workshops using participatory learning approaches were also undertaken to share experiences and challenges field workers encounter as well as the required support to inform identification of capacity gaps.
- Furthermore, validation workshops were conducted in the respective countries of study to share findings with the study teams and stakeholders.

The study was disseminated in a half-day workshop at the 6th CBR Africa conference Zambia in 2018, which was attended by participants from different countries.

Essential Standards of CBR/CBID Training: Findings

Analysis of the essential standards for CBR training was based on the three aspects of study that is profile, training and support accorded to /needed by CBR/CBID fieldworkers.

Profile

The study revealed that there is no uniformity in socio-economic demographic profile of CBR/CBID fieldworkers. The fieldworkers have varying educational background, gender and speciality. Workers are motivated by intrinsic and extrinsic motivation factors. Many are motivated by *'the love of helping out'*, and the possibility of creating change for and by their clients, within households and at the community level. The extrinsic motivation factors are essentially financial.

Although it may not be possible to standardise socio-demographic characteristics of field workers, study participants gave the following suggestions:

- CBR/CBID programmes should endeavour to have a balanced mix of male and female fieldworkers aged 18 and above. This will promote gender equity and effective modelling of gender among programme implementers and beneficiaries.
- Fieldworkers should be grounded in knowledge and skills of community development since CBR is an integral part of community development.
- CBR/CBID fieldworkers should have experience living or working with persons with disabilities. Experience enables field workers to appreciate the needs and living situation of persons with disabilities and their families,

develop positive attitudes and acquire values essential for quality service delivery.
- Programmes take on field personnel with varying specialities. Having workers with different specialities facilitates complementarity in execution of field tasks across the CBR domains.
- Where possible, fieldworkers should come from and live in the area where they work as CBR/CBID interventions ought to be context sensitive.
- Workers need to be people who are curious, innovative and eager to learn. This is partly because the CBR support process is undertaken in dynamic contexts that requires continuous learning, adaptability and resourcefulness.
- Personnel should possess skills in case-management and several generic competencies such as counselling, communication, teaching/training, goal setting and reporting.
- For effective performance of fieldworkers, there should be a balance between intrinsic and extrinsic motivation factors.

Training

The study set out to explore major aspects of CBR training in the six countries of study. Focus was on training setting, eligibility, training content, training methods, duration and certification. Overall, the study revealed variations in CBR fieldworker training in the different countries and programmes. This made it difficult for the study to recommend harmonization of CBR fieldworker training curricula. Nevertheless, the study provided an insight into the current status of CBR training, identified gaps and made suggestions that can be utilized by CBR/CBID managers, trainers, fieldworkers and other stakeholders for effective capacity development.

Training Settings

The study established that CBR training is offered mainly in two settings namely formal and informal. Formal training is conducted in government and non-government owned tertiary institutions and universities as standalone programmes or as courses in related disciplines. Much of the CBR training is offered in informal settings by government and non-government organizations. Such training varies in objectives, target group, course duration, content and training methods. Unlike formal training, which was found to blend theory and practice, informal training was more inclined towards skills development. Most informal trainings were found to be tailor-made in an attempt to respond to capacity gaps identified in the field by various stakeholders.

Eligibility to Training Programmes

Entry requirements for CBR trainings differ depending on whether the training is formal or informal. Formal training programmes require a minimum of educational attainment while enrolment to informal CBR training is often based on considerations such as individual interest, work and lived experience of disability. Thus, formal trainings were found to attract more practitioners

from different disciplinary backgrounds while informal trainings took on persons with disabilities and their caregivers, volunteers and local leaders in addition to practitioners.

Training content

It was found that both formal and informal trainings emphasized knowledge and skills relating to identification and informal assessment, causes, prevention and management of various disabilities in different settings, though at varying levels of coverage and depth. Content focus and coverage were found to be determined among others by the project/programme objectives, nature and level of training, educational and occupational background of trainees and resources available. Further analysis of content covered by different CBR training programmes sampled revealed that many programmes endeavoured to address the whole range of components and elements of the CBR matrix. However, it was noted that organizations tended to put more focus on content that directly addresses their project/programme objectives.

It was also observed that some CBR training programmes and interventions were still based on traditional perspectives of disability and CBR which compromises holistic programming and training. This could imply that such training programmes are not abreast of current developments in the field of CBR/CBID leaving capacity gaps.

Overall, there was a relationship between the competences possessed by CBR/CBID fieldworkers and beneficiaries' needs. However, fieldworkers' endeavours were reported to sometimes be constrained by limited capacities of CBR programs and low socio-economic status of beneficiaries.

Training Needs and Required Competences

The study sought participants' views on what they considered to be capacity gaps of CBR fieldworkers. This was deemed important in informing development of content for appropriate CBR training and required competences. Findings on training needs and competences are presented employing the CBR matrix framework under the subheadings- health, education, livelihood, social and empowerment. In addition, required competences relating to management of CBR programs and training are highlighted.

a) Training Needs Relating to Health

The study participants indicated a need for sufficient basic knowledge and skills to support persons with disabilities. They felt that more emphasis should be placed on knowledge and skills necessary to support persons with cerebral palsy, learning and intellectual disabilities, deaf-blindness, visual impairment and autism spectrum disorders. These conditions were reported to be complex and presented challenges to many CBR fieldworkers and carers in the process

of providing support to children and adults with such disabilities. Other training needs in this domain are:

- Practical - case management - skills related to self-care, activities of daily living (ADL), communication, physical exercises/therapy and problems with incontinence.
- Making, maintaining and the use of assistive devices.
- Various therapies and the coaching of parents in these therapies.
- Identification of disability, doing assessments, setting goals, and developing rehabilitation plans.
- Primary eye health and post-operative care.
- Guidance and counselling of persons with disabilities and caregivers.
- Prevention of disability and secondary complications.

Further analysis reveals that the training needs identified by the study participants in the area of health related to the prevention, rehabilitation and assistive devices elements of the health component of the CBR matrix. Study participants were rather silent on training needs that could arise in health promotion and medical care elements.

b) Training Needs with Regard to Education

It was found that the role of CBR/CBID fieldworkers other than teachers regarding education of persons with disabilities was at the time of the study limited to identification of persons with disabilities, referral and liaison with head teachers to get children enrolled in schools. Study participants felt that CBR/CBID fieldworkers would be able to contribute more to the field of education if they were equipped with knowledge and skills relating to:

i. Organizing home-based educational programmes for children with disabilities and their carers.
ii. Communicating with persons with sensory disabilities including use of sign language and tactile communication.
iii. Child-care and development
iv. Conducting adult literacy and life skills training.

From the above, it is evident that study participants saw a need for CBR/CBID fieldworkers to be enabled to contribute to early childhood and primary education as well as non-formal and lifelong learning for persons with disabilities and their families. However, they did not consider secondary and tertiary education as areas of training need for the CBR/CBID fieldworkers.

c) Training Needs Relating to Livelihood

Livelihood development for poverty reduction was identified by CBR/CBID programme beneficiaries and their respective fieldworkers to be of extreme importance in promoting wellbeing of persons with disabilities and their families. It was deemed important in helping families to cope with the care

and support needs of their persons with disabilities. Study participants expressed a need for persons with disabilities and families to have increased access to formal and informal employment and to microfinance credit. CBR/CBID fieldworkers further expressed the need for persons with disabilities and their families to be familiar with their rights and responsibilities regarding livelihood and knowing existing resources and opportunities and ways of accessing them. The research team, however, noted that the training needs and competences identified by the study participants in this domain relate to self-employment, wage employment, and financial services aspects of the CBR matrix leaving out the important elements of social protection and skills development.

d) Competences with Regard to the Social Component

The study participants identified discrimination as a major challenge to participation and inclusion of persons with disabilities. They expressed the need for CBR/CBID fieldworkers to have sufficient competences in the following areas:

- Knowledge on laws and policies relating to persons with disabilities.
- Skills of promoting rights of persons with disabilities.
- Lobbying and advocacy to facilitate equalization of opportunities for persons with disabilities.
- Communication skills and ways of enhancing socialisation including training in activities of daily living.
- Counselling.

However, they did not express training needs in the areas of relationships, marriage and family, personal assistance, culture and arts, recreation, leisure and sports.

e) Training Needs on Empowerment

There was consensus among study participants that CBR training should prepare fieldworkers to contribute to empowerment of persons with disabilities as individuals and in groups. Participants pointed out a need for CBR/CBID training content for fieldworkers to comprehensively address issues relating to:

- Self-advocacy and political participation of persons with disabilities.
- Development and capacity building of OPDs, CBR Clubs, and Parent Support Groups.
- Community support, mobilisation and participation.
- Access to institutions where persons with disabilities' rights and entitlements can be claimed.

f) Management

Management is an important aspect of the CBR guidelines. Study participants recognized that during the course of their work, CBR fieldworkers take on various managerial roles and responsibilities. These include planning, making

rational and timely decisions, guidance, leadership, communication, mobilization, networking and collaboration among others. CBR fieldworkers were reported to acquire skills in these areas through different formal and informal trainings as well as through exposure. Participants emphasized a need for fieldworkers to be equipped with:

- Effective communication skills.
- Skills for attitude and behaviour change.
- Recordkeeping
- Skills and techniques for follow-up of interventions in the different life domains.
- Awareness raising and advocacy skills
- Skills for networking, referral and collaboration with different individuals and agencies for holistic interventions in all life domains.

In addition, participants expressed a need for capacity development in strategic planning, budgeting, proposal development, report writing, monitoring and evaluation.

Training Methods

It emerged from the study that a variety of methods were employed to conduct different trainings. The methods included lectures, group discussions and presentations, demonstrations, role modelling, case studies, field visits, video clips and gallery walks among others. Methods used depended on the activity at hand, content to be delivered, nature (formal or informal), level and objectives of training, number and characteristics of trainees as well as resources available including time, facilities and equipment. Participants suggested that for effective training, practical methods such as field visits, exchange programmes and regular refresher courses should be emphasized.

Duration and Certification of Courses

It emerged that formal CBR/CBID training has varying duration. While some institutions offer courses lasting a few weeks, others conduct CBR/CBID training over a semester, a year, two (2) years or even three (3) years. With regard to certification, the practice is that training institutions certify participants based on the level of training undertaken. However, this is not the case in instances where CBR/CBID is offered as a course within a particular academic programme.

Unlike formal training, informal trainings last short period ranging from a few days to weeks often depending on objectives of the training and resources available. Issuance of certificates of attendance or participation is the norm.

Support to CBR Fieldworkers

Nature and level of support to CBR/CBID fieldworkers was found to vary with governments, CBR/CBID programmes and civil society organizations. Support

is also dependant on work setting and nature of engagement-whether fulltime, part time or voluntary basis. Generally, fieldworkers receive support in form of remuneration, funds for training, support supervision, training material and equipment as well as transport to implement activities. Other stakeholders that provide support to CBR/CBID fieldworkers include persons with disabilities and their caregivers, community groups, development partners, OPDs and the private sector. The support includes food items, collaboration, financial and logistical support, information and participation in medical/rehabilitation camps among others.

However, some participants felt that the support accorded to CBR/CBID fieldworkers was inadequate and felt that stakeholders could do more. It was also reported that some supervisors of fieldworkers did not have background training in CBR which limits their capacity for effective supervision of CBR/CBID fieldworkers. For support supervision to be meaningful, supervisors should possess adequate knowledge and skills relevant for effective implementation of CBR/CBID.

Study participants submitted that fieldworkers' effectiveness could be enhanced through:

- More active involvement of supervisors in the work of the fieldworkers through monitoring visits, coaching as well as feedback sessions about the quality of interventions made.
- Adequate planning of activities and provision of additional support including provision of loans for buying motorcycles, increased remuneration, clear job descriptions, support in challenging assignments such as assessment and filling registration forms.
- Increased community and beneficiary participation, financial assistance for poor beneficiaries and adequate budgeting for activities/interventions.

Besides appropriate financial compensation for field workers, participants saw a need for fixed-term contracts, health insurance and access to medical services for workers and their families.

Conclusion

This study revealed that CBR/CBID fieldworkers have varied socio-demographic characteristics. This is expected since effective and holistic implementation of CBR/CBID requires a multidisciplinary team with varying skills and competences. These competences are attained through formal and informal trainings that offer varied content and in varying duration depending on need, context and availability of resources. This makes it difficult to compare and to harmonise CBR/CBID training across programs and countries. Nevertheless, the study has provided some essential standards that CBR/CBID trainers and managers ought to consider when designing and implementing

programs. Although CBR/CBID fieldworkers acknowledge support from government, civil society and other stakeholders, this support is inadequate for effective implementation of activities within their mandate. Relevant CBR/CBID support systems should be enhanced to enable effective and holistic implementation.

Recommendations

1. CBR/CBID fieldworkers' training programs are not uniform. They vary considerably depending on their nature, context and program objectives which makes it difficult to harmonize training across programs and countries. Therefore, in order for CBR/CBID fieldworkers' training to be relevant, appropriate training should be preceded by a needs assessment involving different stakeholders to inform its development and effective implementation.
2. Persons with disabilities and their families have various needs. These needs change from time to time due to changes in life realities and the evolving nature of CBR/CBID. This presents a need for every CBR/CBID fieldworker to keep abreast with relevant knowledge, skills and competences to offer support in these changing situations. CBR/CBID programs and managers should therefore ensure that fieldworkers are continuously trained.
3. The study has identified several competence gaps that limit effective service delivery by CBR/CBID fieldworkers. CBR/CBID trainings should be designed and implemented comprehensively to address these gaps.
4. The study revealed that the support CBR/CBID fieldworkers get from government, civil society organizations and other stakeholders is inadequate. This limits their capacity to provide effective services. Stakeholders should be encouraged to increase support to CBR/CBID fieldworkers to enable them effectively fulfil their roles and responsibilities.
5. Networking and referral are key strategies in implementation of CBR/CBID. This is because persons with disabilities and their families have varied needs and yet no single individual or agency can address them all. It is recommended that CBR/CBID practitioners should have adequate training in networking and collaboration with other stakeholders to collectively meet the various needs of persons with disabilities.
6. Some CBR/CBID field workers may not be recognised by employers and other stakeholders due to lack of certification. This can demotivate fieldworkers and curtail their development. CBR/CBID programmes and training institutions should therefore seek accreditation and more funding for their training programmes from relevant authorities.

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Chapter 3

Early Childhood Development and Disability

Carolyne Maholo Sserunkuma, Alice Nganwa, UtaPrehl

Introduction

Sustainable Development Goal (SDG) 4 aspires for inclusive, equitable and quality education for all people in the world and to promote life-long learning (UN, 2015). Target 2 of this goal is to ensure that all girls and boys have access to quality early childhood development, care and pre-primary education in preparation for primary education. This chapter presents experiences of children with disabilities and their families as well as the contribution of CBR practice to Early Childhood Development (ECD). It concludes with recommendations for various stakeholders to promote ECD for children with disabilities.

Early Childhood Development

Perspectives of early childhood development by different scholars and agencies seem to agree on the importance and domains of ECD. However, while a few authorities take ECD to cover developments and experiences children go through from conception to four years, others stretch it to the age of eight. Children's experiences during the early years set a critical foundation for their entire life course. Enabling children to achieve their full developmental potential is not only a human right but also an essential requisite for sustainable development.

While it is acknowledged that every child develops at their own pace, some children may experience significant delay in attaining certain development skills compared to others of the same age in the same setting. Children need, among others, a safe and loving environment, good nutrition, ample play and sleep for optimal growth and development. It is everyone's responsibility to contribute to all these for children to realize their full potential.

Developmental Milestones

Developmental milestones are the various skills observed in children as they grow and develop. Much as every child develops at their own unique pace, there are specific milestones that generally indicate effective child development. For instance, by the age of 3 months, a baby is expected to hold the head up while lying on the tummy, turn to sound, watch things as they move and bring hand to the mouth. By 6 months, a baby is expected to roll over in either direction and sit when supported, by 9 months, she/he is expected to stand at

least with support, learn gestures like waving or shaking head, smile at people, coo or make sounds. Indeed if by one year, a child doesn't sit at least with help, babble ("mama", "baba", "dada"), play any games, respond to sound, recognize familiar people and transfer toys from one hand to the other, the parents/carers should consult a rehabilitation professional for assessment and early intervention.

Child development occurs in four main areas:

1. Cognitive skills: These include learning, thinking and problem solving. These skills are acquired by a child through early stimulation, social interaction and exploration of the environment.

2. Social and emotional skills: These involve the ability for a child to recognize, express and control emotions. The social environment to which the child is exposed from birth is a great determinant of their social and emotional skills development. For example, a child learns to smile and make sounds to communicate depending on the nature and extent of interaction with the people around. Also a child who grows up in a safe and loving environment will most likely be able to ask for help, show and express feelings appropriately, and get along well with others. On the other hand, a child who grows up in an unsafe environment may exhibit timidity, low self-esteem and encounter difficulties in initiating and sustaining social relations.

3. Speech and language skills: This is about a child's ability to use and understand language. Speech and language development is facilitated by many factors. For example, with sufficient exposure to communication sound, a baby learns to coo and babble in preparation for speech. Despite their inability to speak, talking to children right from birth helps them to develop cognitive skills required for understanding what is said and later on use words in ways others can understand. The social environment is therefore a great contributor to speech and language development.

4. Gross and fine motor skills: Gross motor refers to ability to move large muscles like turning the different body parts such as rolling over, sitting, standing and walking. Fine motor is the ability to use small muscles such as touching things, picking small items, holding a spoon or pencil and turning the wrist to write or to open a door. Both gross motor and fine motor skills are important in child development because they enable the child to perform tasks such as movement and other daily living activities. Like other domains, gross and fine motor skills development is dependent on a variety of factors. For instance, a healthy child who gets good nutrition, timely immunization and exposure to conducive play and

other forms of interaction is likely have optimal development of gross and fine motor skills.

Much as acquisition of one skill contributes to attainment of other skills, lag in a child's attainment of one skill may not necessarily indicate a developmental delay. Every child develops at an individual unique pace. It is also important to note that maternal wellbeing is a great determinant of child growth and development. Mothers need safety, emotional stability, good nutrition and a loving environment before, during and after pregnancy to nurture their babies for effective growth and development.

The home environment provides the first learning setting for a child. A conducive home mood, good social interaction, adequate exposure to speech and communication, sufficient lighting in rooms, good nutrition, hygiene and sanitation and ample security in a home are some of the key requirements a child needs to attain the developmental milestone.

The following case study illustrates the role of social interaction at home in

Box 1

Mlozi's Story: Mlozi Learns to Speak

In a pre-school facility in one community in Southern Africa, a parent came in with Mlozi, a 4 year old boy. At this age, Mlozi had not developed speech and had poor social skills. He was aggressive, destructive and could not interact well with other children.

The first suspicion at school was that Mlozi had a hearing impairment. So he was referred for assessment. However, no problem was found with his hearing ability. Mlozi was enrolled in the school. Effort was made to involve Mlozi in all activities including playing, singing, dancing, coloring, molding, reading and writing. His teacher advised the mother to reinforce learning at home, talk to Mlozi and as much as possible involve him in home activities.

Despite his inability to speak, Mlozi did his best to learn. After a few months, it was noted that Mlozi was gradually transforming and progressing well in all learning areas. He had become calm, friendly and interacted better with other children. He also followed rhythm as children sang and eventually started to emit some sounds. With time Mlozi acquired and mastered speech.

Today, Mlozi is a brilliant boy thanks to the stimulating environment he found at school and the eventual support of the family.

facilitating speech and language development in children.

About Mlozi and his family

Mlozi, is a first born. Both of his parents work and are barely at home. They often returned late and exhausted due to hectic schedules. They had limited interaction with Mlozi. The house-maid with whom Mlozi was entrusted spent most of her time listening to music off her mobile phone with earphones. She hardly talked to Mlozi, did not involve him in any activities and rarely interacted with him.

What lessons can be drawn from this case study?

- Sustained intimate interactions by parents and other family members largely contribute to optimal child growth and development. However in some communities, this is often undermined by challenges relating to heavy work schedules of some parents, social engagements, obsession with social media and electronic devices among others.
- A child learns speech from communication that occurs within their environment. Talking to infants, for instance, when feeding them, dressing them and while carrying on with daily house chores is very helpful for speech development.
- Peer interaction such as through play and other children activities provides a stimulating and good learning opportunity for optimal child development.
- ……
- ……
- ……

Exposure and Stimulation

Stimulation and exposure are a major determinant of child development. Child development is often facilitated by stimulation and exposure to various items, activities and events. For example, exposure to sound may encourage a child to follow sound. Also, exposure to items, usually colored objects enables a child to follow them and with time reach out for them. Children generally explore using their senses of sight and touch. A child with a visual impairment will most likely miss out on this if no deliberate effort is made to stimulate that child. Bright colors and sufficient lighting enable children to maximize their visual ability for effective child development. In the African settings especially in rural areas, mud houses as depicted in pic 1 are popular. These usually have a single door with a dark interior. Such unstimulating environment may restrict children's learning and development.

Pic 1: A typical African Homestead in Northern Uganda

In Africa, it is common practice to keep children with disabilities indoors. Reasons relate to safety, fear of public shame, allowing caregivers time to engage in other work among others. Spending a lot of time indoors may compromise a child's ability to see, explore and learn. Smearing mud walls with light ash to brighten the room could make it more stimulating. In addition, enlarging windows helps to enhance ventilation and lighting. Bringing the child out of the house to enjoy the fresh air and bright sunlight greatly helps. If by the age of six months a child doesn't follow objects, despite use of bright colors and exposure to light, a parent may need to consult a medical or rehabilitation personnel for assessment and early intervention.

On confirming visual impairment for this child, all is not lost. Early intervention by among others helping the child to explore the environment and training them in activities of daily living enables participation. Children with visual impairment often learn to cope by maximizing use of their other abilities including residual vision if any. Delays in development of children with visual disabilities can be mitigated by talking to them, giving them an opportunity to feel items, smell them and help them to learn different objects and their uses. Introducing the sense of order is equally important for such a child with visual impairment. It enables the child to easily trace items on his/her own and to grow up with relative independence.

Early Identification of Disability and Appropriate Intervention

Early identification of disability in children is crucial for planning timely interventions and mitigating developmental delays. Early intervention may prevent development of secondary disabilities in children. The story below attempts to illustrate this.

Nansikombi's Story: Locked out of the World

Nansikombi's mother narrated:

"…. from childhood, we realized that Nansikombi does not understand anything. She does not talk, never follows instructions and can never do things right. For instance when you send her to bring a knife, she will go running to fetch water from the well. Her younger sisters and brothers are different. We did all we could and failed to break through with her. We have been to hospitals, and traditional practitioners with no results.
When we got her siblings and they help with all we need, we decided to stop giving her tasks, after all, she does not understand anything. Later, she started ruining everything. Behaving like a person with a mental problem. She would find milk boiling and adds soap, finds you washing and adds cooking oil …… so we took her to the psychiatry center. She has been there on a number of occasions and each time, they tell us that she has no mental problem!
These days it is worse. She beats people even when they are just passing on the road. We have had many issues with the local council so we decided to put a leash and control her there.
We don't know what else to do. Nansikombi is a very big problem…."

Nansikombi, aged 14 years, lived with her parents in one suburb of Kampala. One day, she was found by a CBR worker tied with a leash, next to a cow that was grazing under a big tree in the home. Nansikombi was eating food served in an old cooking pot. Puzzled by this situation, the rehabilitation worker reached out to the mother and asked her what was happening with the girl. The mother explained that she had to tether the girl in order to restrict her movement and to prevent her from harming people in the neighborhood. When asked why Nansikombi was served food in a pot, the mother explained:

> *"We serve her in that pot to avoid spilling food which is common whenever she is served on a plate*. Even then, *she often pours the food on the ground and continues eating it there ……."*

The CBR worker further learnt that Nansikombi had recently returned from a psychiatry center where she had been taken by her parents for psychiatric intervention.

A lot can be learnt from this case study:

1. Despite living with Nansikombi for 14 years without developing speech, her parents neither knew nor suspected that Nansikombi had a hearing impairment. Consequently, they did not intervene appropriately which resulted into a communication gap between the family and the child. This in turn resulted into violent behavior by the girl probably to draw attention.

Imagine yourself in an environment where all people around you speak a strange language. They laugh and go about life without noticing you!

2. Many children with hearing impairment are not identified early. They are mistaken to have learning difficulties and mental challenges. Consequently they are labeled and excluded.

3. Children with hearing impairment partly cope by observing behaviour of people around them. The children endeavor to use the best of their imagination to respond to instructions. However, more often than not communication gaps and misunderstandings arise. The subsequent miss-match frustrates family members and with time, they give up on the children. All people regardless of disability love to feel part and parcel of the setting in which they live. For example, in a home, a child loves to be assigned tasks and to feel appreciated like all others. Feeling neglected may make children resort to destructive behavior. In a way, this pays off because it at least draws attention. Parents often experience this with children with disabilities. In this case, it is possible that Nansikombi became violent to the community in order to draw attention. Nansikombi's experience is a human right violation that arose from ignorance and desperation.

In an attempt to ease the situation, the rehabilitation worker asked Nansikombi's mother to untie the girl and clean her up. Later, the worker carried out a basic assessment. She realized that Nansikombi could be having a hearing impairment and referred her to a specialist for further assessment. In addition, the rehabilitation worker encouraged the family to initiate communication with the girl through gestures. The worker also asked them to involve Nansikombi in household activities such as cooking, washing and cleaning the house.

After some time, the CBR worker made a follow up visit to Nansikombi's home. She noted that:

- Results from the specialist's assessment confirmed that Nansikombi has significant hearing loss.
- Use of gestures facilitated Nansikombi's communication with the family members and neighbors. This gradually contributed to attitude change

and enhanced Nansikombi's involvement in family and community activities.

- Communication improved Nansikombi's interaction and behavior.
- Nansikombi's participation in household activities had paid off. The young girl was happy to be washing utensil, and engaging in activities around the home. She had ceased to be violent and was an active family member.
- Peace and harmony were restored at home and in the community thanks to the interventions.

The rehabilitation worker urged the father to consider enrolling Nansikombi in a nearby school. She further requested Nansikombi's mother to endeavor to train the girl in life skills including sexual and reproductive health.

Disability and Early Childhood Development

Approximately 15% of the world's population are reported to have some form of disability 80% of them live in developing countries (WHO, 2011). One in every twenty children of 14yrs and below have a disability (UNICEF, 2013). Their wellbeing is undermined by limited access to educational, medical, social and other rehabilitation services including early childhood care and development that are required for optimal physical, social, emotional and cognitive development.

Interventions for early childhood development such as providing children with opportunities to play, good nutrition and healthcare, immunization, talking to children, maternal and family wellbeing tremendously contribute to optimal development of their motor, cognitive, emotional, social and communication competences. In spite of these benefits and commitment by governments, access to quality early childhood care and development by children with disabilities in Africa remains a challenge. For example, the African Union notes that pre-primary education across the continent is severely underdeveloped, plagued by disparities, poorly managed and lacks coherent curricula and relevant linkages with primary education (CESA 16-25) Similarly, despite development of early childhood development policies and programs by governments and civil society in the continent, these initiatives have limited emphasis on children with disabilities and are not effectively implemented.

In many African countries, early childhood interventions for children with disabilities are faced with a number of challenges. Maternal health is critical for child development during the prenatal stage. However, in Africa, this is undermined by high poverty levels, food insecurity, poor nutrition, disease burden, limited knowledge and information on benefits of maternal health and available services, long distance to health facilities and limited skilled health personnel with receptive attitude to expectant mothers.

The experiences children with disabilities get during the early years of life impact not only their early childhood but their entire life course. For many, optimal child development is not possible because of various impediments. In many low income countries, children with disabilities live and grow in situations that expose them to malnutrition, under stimulation, limited access to immunization and other healthcare services. They live in unconducive environment, have limited family support with carers hardly knowing what to do or where to go for support. In many instances, they have limited access to rehabilitation services such as home-based care, appropriate therapies and assistive devices. Children with disabilities often experience discriminatory attitudes and practices from family and community which restrict their participation and access to services.

In many developing countries, causation and management of disability remain a mystery because of myths, misconceptions and unpleasant beliefs associated with disability. In a few instances, the coming of a child with disability draws the family together to support the child. However, in many cases, presence of a child with disability tears the family apart. The mother is often blamed not only by the father but other family members for the 'disgraceful' occurrence and 'shame'. This results into the man abandoning the mother with the child usually leaving them with hardly any financial, material and social support. Such situations impede children with disabilities' access to ECD, rehabilitation and other basic services.

In addition, children with disabilities have limited access to pre-primary school facilities. In many countries, these services are not inclusive, are privately provided, are urban based and are too expensive for poor families to afford. The other challenge at hand is limited trained and competent personnel in early childhood education (ECE). Even then, the few available trained personnel have limited capacity to effectively support children with disabilities in ECD due to lack of exposure and specialized training on disability.

Examples of Good ECD Practices for Children with Disabilities

CBR provides a good opportunity for early childhood development of children with disabilities. The stories below illustrate the contribution of CBR to ECD:

1. CBR Community Practice and ECD

At the end of each academic year, CBR students of Kyambogo University, Uganda have eight weeks of community practice in their community settings. During community practice, each student is expected to identify and work with at least ten people with disabilities, their families and community. Students profile and undertake basic assessment of each of the identified persons with disabilities and develop appropriate individualized intervention

plans which they endeavor to implement together with family members, community development officers and with support supervision from the university. During this exercise, the students identify, network and collaborate with different stakeholders in the community including parents' support groups, health facilities, schools, organizations of and for persons with disabilities and government programs among others. Below is an account of one Kyambogo University CBR student's experience of community practice.

Nyaburu, a Child with Spina Bifida

During community practice in Eastern Uganda, the CBR student identified and worked with Nyaburu, a two months old baby girl with spina bifida and hydrocephalus. According to the mother, Nyaburu was born with a lump on the lower back. After a few weeks she noticed that the child's head was increasing in size and with time she developed nasal congestions and began to experience difficulty in breathing. That is when Nyaburu was rushed to a health facility. At the health centre, Nyaburu's mother was told to take her to the regional referral hospital for further management.

Unfortunately, Nyaburu's mother failed to take the child to where she was referred. She could not afford transport let alone upkeep and medical bills in the urban health facility. Nyaburu's mother lived alone with her two other children in a single rented room in rural Eastern Uganda. The father to the children abandoned them shortly after realizing Nyaburu's condition. Her only source of livelihood was occasional causal labor in the neighborhood.

The CBR student networked with civil society organizations in the area, mobilized resources and went with Nyaburu and the mother to a rehabilitation health facility for intervention. At the hospital, the medical personnel assessed Nyaburu, explained her condition and immediately scheduled her for medical intervention. While nursing Nyaburu at the hospital, her mother was taught to care for Nyaburu and support her growth and development. The CBR student was also given information on how to support Nyaburu and her family at home.

After three weeks of hospitalization, Nyaburu was discharged and returned home. The CBR student explained Nyaburu's condition to the siblings and encouraged them to be supportive. She also encouraged Nyaburu's mother to join a parents' support group in her community for peer counseling and shared learning. At the end of the first community practice, the student handed over Nyaburu to the community development officer and civil society organizations with whom she worked for follow up.

One year later, the student returned for the second community practice and visited Nyaburu's family for follow up. The student was happy to find that Nyaburu was slowly progressing in development. She however had urine and

bowel incontinence. Mobility was also still a challenge. In addition, the student learnt that Nyaburu's mother had joined a parents' support group. In the support group, Nyaburu's mother met other mothers with children of different disabilities. They shared experiences and ways of managing their children's conditions and meeting their needs. In the group, the mothers were introduced to various income generating projects. Nyaburu's mother learnt mushroom growing, poultry keeping, bee keeping, home gardening and craft work. As a result, she had a vegetable garden at home and business in craft work. Money generated from this enabled her to afford food, healthcare and other basic needs for the family. Furthermore, the student found that Nyaburu's father had returned home and had become supportive. He was anxious to learn more about how Nyaburu could be supported to continue progressing. The student went with Nyaburu and her parents to a physiotherapy unit in the nearby referral facility where they were taught range of motion exercises, urine and bowel management for Nyaburu. The students encouraged Nyaburu's siblings to interact and play with Nyaburu as she exercised. She also introduced adapted play and various self-help skills for the family to continue teaching Nyaburu. At the end of the eight weeks' engagement with the family, the student was glad to leave the family re-united, progressive and empowered in supporting Nyaburu and other children.

2. A CBR Worker's Experience with ECD

Many civil society organizations undertake several activities with persons with disabilities, their families and communities. Some of these organizations engage in CBR and ECD. The story below is about an experience of a CBR worker in Monze, Zambia.

Ngema, a Child with Significant Developmental Delay

Ngema, a six-year-old boy was identified by a CBR worker in a rural community in Monze, Sourthern Zambia. Despite his age, Ngema spent most of the time lying because he had not attained any developmental milestone. Ngema a first born had a two-year-old sister, Amanaki. Unlike Ngema, Amanaki was joyous. She spent most of the time playing and helping with simple tasks in the home. Preliminary assessment of Ngema revealed that he had quadriplegia. Interaction with Ngema's parents revealed that they had given up on him. They did all they could and got tired because they did not know what to do with him anymore. Ngema's mother did not know how to care for him. Compared to his sister, Ngema was malnourished. The CBR worker talked to Ngema's parents about his condition and they together listed his needs. Since Ngema spent most of the time lying on the bed, he was developing a curve in the spine and had pressure sores.

The CBR worker trained Ngema's parents to position him in the corner of the house with a cushion on one side to mitigate the curving of the spine and enable him feed better. She also trained them to provide range of position exercises. Amanaki was encouraged to always come around with the other children she played with in the neighborhood to play with Ngema while he sat in the corner. Since he had challenges with toileting, the CBR worker went with Ngema's father to a carpenter and talk to him about making a corner seat with a toilet hole. She explained the toilet seat to the carpenter and brought him home to take Ngema's measurements for an appropriate toilet seat. Two days later, the carpenter brought the toilet seat to which Ngema was introduced. The family was oriented on the use, care and maintenance of the toilet seat. Ngema started using the toilet seat immediately and this helped to improve hygiene.

After a few weeks, the CBR worker realized that Ngema brightened up each time the little girls and boys came to play with him. He began to show interest in some play items although he could not reach out for them. Family members continued to provide range of motion exercises to Ngema and the children also helped during play. After e few months, Ngema gained some strength in the left arm and leg with which he began to play with other children. He began to crawl and reach out for items that interested him. He also liked watching the mother while she washed utensils and always enjoyed helping out. However, the CBR worker's engagement with Ngema and his family came to a halt when the family relocated after his father got a new job opportunity in the city.

Promoting Early Childhood Development for Children with Disabilities

Promoting ECD is not only critical for optimum growth and development but a human right whose realization requires combined effort of different actors including Governments, civil society, families, communities, service providers, training institutions, organizations of persons with disabilities and children with disabilities. To promote ECD for children with disabilities in developing countries, the following among others need to be considered:

1. Governments should not only develop disability inclusive ECD policies and programs but also ensure their effective implementation with sufficient financial support.

2. Stakeholders ought to acknowledge and value human diversity, and recognized that ECD interventions may differ from one context to another based on culture, social and economic circumstances as well as nature and degree of disability.

3. Children with disabilities and their families have varying needs. This calls for adoption of a twin-track approach and multi-sectoral collaboration among stakeholders.

4. ECD starts before a child is born. Therefore, ECD interventions should be designed to ensure maternal and child wellbeing. In addition, ECD programs should establish mechanisms for early identification, assessment and intervention.

5. The experiences a child undergoes in the period before starting formal education is critical. ECD programming should emphasize community based interventions that enable holistic development. These should include activities that promote play, stimulation, nutrition, healthcare, child safety, hygiene and sanitation, activities of daily living, self-care and esteem, pre-school skills and environmental modification. Programs should endeavor to raise awareness and demystify disability, build capacity in parenting children with disabilities and improve livelihood.

6. ECD interventions should mobilize and build capacity of different stakeholders including children with disabilities, families, organizations of persons with disabilities and communities through human rights awareness raising, promoting parents' support groups and child rights clubs among others to facilitate self-advocacy.

7. ECE training curricula should be made holistic and disability inclusive to empower teachers to provide reasonable accommodation in schools. This will not only facilitate enrollment of children with disabilities in existing ECE centers but also enable the teachers to address the children's varying needs.

8. Training institutions in health, education and social development should incorporate holistic inclusive ECD in the training curricula to enhance competence in meeting the varying needs of children with disabilities in mainstream settings.

9. Providers of mainstream community development programs should incorporate holistic inclusive ECD to enable children with disabilities to benefit from these existing programs in contribution to the sustainable development goals.

Conclusion

A child's experiences in the early years of life impacts his/her entire life course. Early childhood development therefore lays a firm foundation for optimal child growth and development. ECD interventions are a human right and an essential requisite for sustainable development. Unfortunately, in many developing countries, children with disabilities are often excluded from ECD

due to many factors. CBR/CBID should be embraced as an effective strategy for promoting ECD for children with disabilities and their families.

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Chapter 4

CBR/CBID Training in Africa for Resilience and Inclusive Development

Victor Locoro, Dryford Mpunga, Carolyne Maholo Sserunkuma,

INTRODUCTION

Community Based Rehabilitation (CBR) has been implemented in developing countries for over four decades to improve the well being of persons with disabilities and to promote their inclusion in community development. It helps to build resilience of individuals, families and communities. Like many other service disciplines, implementation of CBR/CBID requires continuous training at different levels. This chapter highlights CBR/CBID training by different stakeholders in Africa in different contexts.

Community Based Rehabilitation/Community Based Inclusive Development

Community Based Rehabilitation (CBR) was originally introduced to increase access to rehabilitation services in communities. However, over years, it has grown into a rights-based approach for mainstreaming disability in all spheres of development. CBR involves measures undertaken to empower persons with disabilities and to create an enabling environment to ensure their participation and inclusion at individual, family and community level. It is the preferred approach for promoting equalization of opportunities and active participation of persons with disabilities in low resourced environments as it emphasizes use of locally available resources and existing structures.

CBR has evolved into a world-wide strategy and movement, based on inclusive community development principles. It is a multi-sectoral approach with five interrelated major components of health, education, livelihood, social and empowerment. These components together with their respective elements form the CBR matrix which outlines the structure and content of the CBR Guidelines launched by WHO in 2010 to guide promotion of disability inclusive development (WHO, 2010).

The declaration of the Sustainable Development Goals in 2015 increased advocacy for inclusive development and sparked debate among some stakeholders on whether or not it was the right moment for CBR to evolve

further into Community Based Inclusive Development (CBID). CBID is said to be a people centered, community driven and human rights based approach that addresses the challenges experienced by persons with disabilities, their families and communities. Despite the controversy in individual perspective, CBR/CBID is geared towards a common goal; ensuring access to services and facilities by all including persons with disabilities. Successful CBR/CBID requires capacity development of individuals, families and communities to identify the respective needs of persons with disabilities, available resources and facilities to develop appropriate strategies to improve their lives.

CBR/CBID for Resilience Building

CBR/CBID is an appropriate resilience building strategy since it involves empowerment and enablement of persons with disabilities to engage in individual, family and community activities with maximum use of locally available resources. Resilience refers to both a process and outcome of successful adaption to difficult or challenging life experiences. Resilience empowers people to accept and adapt to situations and move on.

Resilience building is about empowering individuals, families, organizations and communities to own up to their challenges. It involves developing their capacity to identify their challenges, threats, opportunities, existing resources and facilities to generate appropriate strategies that can facilitate transformation of their lives. Many programs involved in CBR/CBID and disability work undertake several activities some of which are directed to this cause.

Training is a major element of effective CBR/CBID. Without CBR/CBID training, resilience and sustainability of rehabilitation and inclusive development interventions are unattainable. CBR/CBID training is experienced at different levels and settings as formal, informal and non-formal learning to and by service providers, individuals, families and communities respectively.

Formal CBR Training

Formal CBR training is provided by academic institutions in different parts of Africa. In Uganda, formal training in CBR and inclusive development is offered by Kyambogo University – a public university, and COMBRA, a non-governmental organization.

CBR and inclusive development courses develop trainees' capacity in identification, assessment and intervention in the different cases of disability using locally available resources to improve the lives of persons with disabilities, their families and communities. The courses provide an

opportunity for students to undertake community practice/fieldwork using the acquired knowledge to develop competencies while offering a service to communities.

During community practice, students work with persons with disabilities at individual, family and community level. They identify persons with different disabilities with consideration of impairment, age and sex among others. For each identified individual, students work with families to assess basic and rehabilitation needs, existing resources and opportunities which inform development of appropriate intervention plans. Such interventions may include, referral for further assessment and intervention from rehabilitation personnel and any other service provider based on need. They also identify stakeholders with whom they network and collaborate to improve the quality of life of persons with disabilities. Below are students from the department of Community and Disability Studies undertaking community practice.

Carol and Victor, these pictures are not well displayed, some notes are hidden

Pic 1: Kyambogo University CBR student assessing a child with mobility challenge during community practice.

Pic 2: Kyambogo University CBR student trying out a locally made walker made for a child with movement challenge

As a course requirement, each student is guided to produce at least one appropriate assistive device using locally available resources for a specific individual met during community practice.

Pic 3 & 4: Some of the assistive devices produced by Kyambogo University CBR students

These products are examined by a team of university staff to assess their appropriateness in meeting the needs of the individuals for whom they are made. Emphasis on the use of local resources is meant to minimize costs, facilitate ownership and ensure sustainability of interventions.

Among the aspects CBR students cover during community practice are provision of basic physiotherapy and occupational therapy skills, use of locally available resources to make appropriate assistive devices, promoting food security and livelihood development, good hygiene and sanitation to minimize health expenses, promoting saving and investment as well as effective utilization of the available resources for sustainable development. Empowerment of persons with disabilities facilitates their participation and contributes to poverty reduction. This enhances their resilience, creates a sense of security, esteem and enables self-actualization and realization of full potential.

Non-Formal CBR/CBID Training

Non-formal training in CBR/CBID is undertaken by different organizations in the different parts of Africa and in different forms. While some of these trainings are conducted over short period of time, others run for months. In Uganda for instance, non-formal training in CBR/CBID is undertaken by COMBRA and many other civil society organizations. Likewise, Kyambogo University students to undertaken on-formal CBR/CBID training through community practice and fieldwork. Such trainings focus on orientation and mobility, training in activities of daily living, home based care, basic physiotherapy and occupational therapy, toilet training, livelihood development, training in appropriate communication for persons with sensory impairments, use of locally available resources to make and maintain assistive devices among others. Non-formal training in CBR/CBID is often conducted by rehabilitation professionals and community resource persons such as persons with disabilities, parents and disability leaders. Non-formal training in CBR/CBID increases coverage of community based interventions for persons with disabilities which contributes to resilience building for inclusive development.

Also in Africa, different training institutions and civil society organizations occasionally organize tailored courses for service providers and other stakeholders in CBR/CBID. Since the declaration of the Sustainable Development Goals, tailored trainings have been undertaken in disability inclusion to match the current development agenda. Such tailored courses are usually organized using participatory learning approaches for appropriate needs identification, harness indigenous knowledge and available resources to ensure ownership. Using results-based planning, trainees in many instances are empowered to identify policy gaps and existing barriers to participation of persons with disabilities for effective advocacy, disability-inclusive planning and intervention.

Malawi's CBR/CBID Harmonized Model

In Malawi, an attempt has been made to harmonize CBR and CBID. Malawi developed a harmonized model for implementing CBR/CBID driven by

government in collaboration with other stakeholders. This model is built on the framework of the CBR Guidelines, the Malawi Republican Constitution and Disability Act as well as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and Sustainable Development Goals (SDGs). Its objective is for disability to become an integral part of development initiatives considered at all levels. Development and implementation of the model is designed to ensure that government plays a pivotal role in mainstreaming disability. Through this model, implementation of CBR/CBID is a responsibility of local councils who plan, budget and ensure disability inclusion in all development initiatives. The model utilizes the local government development structure for both government and civil society initiatives to deliver services to persons with disabilities. This is aimed at creating ownership and to contribute to sustainability since local councils champion planning, resource mobilization and implementation of CBR/CBID. Also, stakeholder collaboration and coordination minimizes duplication and facilitates effective resource management.

CBR/CBID Training Packages

Implementation of Malawi's harmonized CBR/CBID model necessitated capacity development at central government, local council and community level. This created a need to develop training packages with a specific curricula and training materials for knowledge and skills development in disability mainstreaming. The training was intended for key stakeholders and persons with disabilities to play a central role in the process.

Malawi Council for the handicapped, (MACOHA) supported by Norwegian Association of Disabled (NAD) worked with other stakeholders to develop standardized training materials. They blended local material with international resources to develop materials suitable for the Malawi context and many similar settings. The training packages were developed using participatory learning approaches and provide comprehensive information on CBR/CBID components.

A total of 4 training packages with 30 modules each were developed for 4 particular local development levels namely - national, district, community level and for volunteers. A team of 25 national Trainer of Trainers (TOT) was identified and empowered to rollout CBR/CBID training. As part of

implementation, mentorship of service providers was carried out. To facilitate government political will, officials such as Principal Secretaries (PSs), Directors, and the district council officials responsible for implementation of CBR/CBID were oriented.

The following lesson were drawn in the process of developing the training packages and rolling them out:

- Development of training packages requires adequate funding for capacity development and rollout.
- Regulating and monitoring of delivery and use of training material is challenging because of involvement of various parties in getting services to persons with disabilities.
- Need for continued mentorship and monitoring is critical for the desired program results to be realized.

The standardized CBR/CBID training materials help in harmonizing and strengthening capacity building for disability inclusion in development initiatives at all levels. This calls for continued government funding, stakeholder collaboration and a pool of skilled resources persons.

Conclusion

In many African communities, CBR/CBID interventions help to address the limited access to relevant rehabilitation services and promote inclusion of persons with disabilities. Such interventions also help to strengthen the resilience of persons with disabilities, their families and communities. However, for these interventions to yield the desired results, capacity development is required at different levels. Some stakeholders have developed unique initiatives to harmonize CBR and CBID in line with the current global development agenda. Malawi, with support from NAD, is implementing a harmonized CBR/CBID model with standardized training materials for capacity development. This however, calls for continued funding and collaboration by stakeholders to harness existing resources for sustainability.

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Chapter 5

Village Savings and Loan Associations: An Opportunity to Empower Persons with Disabilities

Hubert Seifert

Introduction

Financial exclusion of marginalized communities has created a need to develop indigenous community-based solutions. Traditional savings groups have been in existence for long and are wide spread in villages in Africa, Asia and Latin America where formal financial services are largely absent. Such informal entities, technically referred to as Rotating Savings and Credit Associations (ROSCAs), are known by different names in different regions of the world. This chapter highlights experiences of Village Savings and Loan Associations in Africa.

Village Savings and Loan Associations

Village Savings and Loan Associations (VSLAs) are made up of community members in rural areas that do not have easy access to formal financial services. They pool their savings, offer loans at self-determined interest rates and manage a social fund. They are trained on managing their resources more effectively and gain knowledge on how to start their own micro enterprise. They are self-managed and low cost groups that do not receive external capital and after one year of operation become self-sustaining.

VSLAs offer social security in communities that are often vulnerable to economic shocks like illness, death or disasters thus offering safety nets for relief and subsistence. Financial vulnerability in rural areas is a key driver of poverty and unstable income. Therefore, VSLAs help their members to better manage irregular cash flow that largely comes from agricultural harvests by ensuring that members find other ways to generate income, start and grow their savings.

At the 6th CBR Africa Conference in 2018 good practices of VSLAs from CBM supported projects were shared. These practices reveal that VSLAs are a viable option for the financial inclusion of persons with disabilities. However, becoming a member of a VSLA implies that persons with disabilities are able and willing to provide the weekly or monthly savings amount required. It also requires that mainstream groups are willing to accept persons with disabilities as members. This has often proved difficult since these groups, like society in general, tend to exclude persons with disabilities. As a response to exclusion, some organizations mobilized persons with disabilities to form their own

VSLAs. Such groups have been successfully established in Uganda, Rwanda, Democratic Republic of Congo (DRC) and Ethiopia including about 50,000 persons with disabilities. The following section describes key steps for initiating and running VSLAs. In addition, strength and challenges are identified.

Setting Up and Running VSLA Groups

There are varying ways of setting up and running VSLAs based on context. Many VSLAs are usually based on the procedures agreed upon by members of the group. Below are the key elements often considered in setting up VSLAs.

Expression of interest to join a VSLA

An external agency such as NGO may introduce the concept of savings and loan groups to the community and then facilitates the formation of VSLAs comprising of 15 to 30 members. This is often concluded by encouraging member to express interest in forming a group. Because trust is fundamental to the effective functioning of a VSLA, group members vet among themselves to confirm membership.

Training

This is provided over a few months to help members define the VSLA's purpose, develop the constitution and rules, elect members to serve as officials, and set terms for savings and loans, including interest rates, repayment schedules and penalties for late payments or missed meetings. The group is also trained in the procedures on how to collect savings and approve loans, record transactions, and run weekly meetings. The methodology offers simple recordkeeping techniques suitable for literate or illiterate people. Members receive savings books that reflect payments and loans.

Governance

Each VSLA elects a chairperson, secretary, treasurer, and two money-counters who form its executive committee. In addition, members select three others and entrust each with a key to one of the three locks on the cashbox where the group's funds are kept. This governance structure serves as an internal control system. All transactions – the collection of member savings and the disbursement of loans – are carried out at weekly meetings in front of all members, ensuring transparency and accountability.

Financial Services

VSLAs embark on collecting periodic savings from members. Savings are accumulated in the form of shares at a price agreed upon by the group. Members can buy 1 to 5 shares at every meeting depending on their incomes. The use of shares simplifies recordkeeping. Once sufficient savings have accumulated in the cashbox over four to five weeks, loans are offered to

members. The groups usually set interest rate for loans from around 5 to 10 percent monthly. At the end of the year, members receive a return on their savings ranging from 30 to 60 percent annually generated from interest and fees collected throughout the year. In addition, VSLAs set up an insurance fund, often called a social fund, to enable members to access money in emergencies or at particularly vulnerable times. The group determines if the emergency funds are distributed as grants or as interest-free loans with flexible repayment.

Audit

Usually one year after the VSLA is formed, the group conducts an "action audit" whereby it pays out savings and earnings from interest and fees, closes its books, and starts a new cycle. The action audit is usually timed to provide a lump sum to members at critical times in the year when access to money is needed, for example to pay for school fees or inputs at the start of the agricultural season. It also enables members to leave the group and new members can join. Most groups reconstitute themselves and resume the savings and loan process.

Agency facilitation

In cases where an external agency such as NGO initiates establishment of VSLAs, agency facilitators are assigned to the group for support supervision. This is often provided to the VSLAs from the start of operation to the time of the first action audit. The agency facilitator observes groups' meetings and supports the executive committees as needed to ensure that procedures and systems are working well. If there are no issues, the groups function independently thereafter. The agency facilitator keeps a record of the performance of the groups for monitoring purposes.

Strength of VSLAs

Group cohesion: Because groups are formed based on trust, social cohesion is often realized among members. The social fund contributed by group members comes in handy to help individuals during emergencies.

Rural and poverty outreach: VSLAs operate in remote or sparsely populated areas where mainstream formal financial services may not be readily available.

***Low operating costs*:** Unlike Micro Finance Institutions, VSLAs operate with minimal or no investment in infrastructure, transport, communication and personnel costs. Cost per member for the startup of VSLAs usually range from an average of $20 to $60 and $10 to $30 in Africa and Asia respectively.

***Capital remains within the group*:** Interest paid on loans remains within the group, and builds the cash assets of the members. This is highly motivational to members since they earn significant returns on their savings.

***Transparent, democratic and flexible*:** Members determine their own rules and decisions are made through consensus with minimal paperwork. Members save on a flexible schedule agreed upon by the group and can vary the amount saved each period. Because members usually know each other well, there is more flexibility in offering quick loan disbursement and individualized repayment schedules. Saving is flexible since members can save 1 to 5 shares depending on their incomes.

***Client debt level*:** Loans are matched to each member's capacity to repay, based on the group's decision. Loans are usually short term and are approved by consensus.

Conduit for other interventions: Some agencies use groups to provide other services such as health education, entrepreneurship training, advocacy for disability rights, climate change adapted farming, nutrition and HIV/AIDS awareness among others.

***Opportunity for increased economic activity*:** Where personswith disabilities and other vulnerable people are involved, VSLAs are a first step towards financial inclusion. While some groups will never link to the formal financial system, others will leverage their learning about financial services in the group context to seek access to more formal and a wider array of financial services. Members who aspire to access larger loan beyond the capacity of the group savings are referred to mainstream financial institutions.

Constraints of VSLAs

***Limited capital*:** Since VSLAs depend on members' limited savings capacity to provide the group's lending capital, loan demand by members can outpace supply. This compels members who want larger loans to resort to the mainstream financial institutions.

***Interrupted savings*:** The yearly distribution of savings and caps on shares interrupt members' efforts over time to accumulate large amounts of capital.

***Domination by individuals*:** Some group members may exploit the loan fund by taking more than their share of loans and by defaulting. This can be mitigated by placing a cap on the number of shares (savings) to be purchased by any one member and restricting loan amounts to multiples of shares held.

***Exclusion*:** Since groups are based on expression of interest, poorer and vulnerable individuals may be excluded in mainstream VSLAs.

***Theft*:** Cashboxes are kept by the group members and may pose a risk of theft.

Benefits of VSLAs to Persons with Disabilities

Empowerment. VSLAs empower persons with disabilities to participate and contribute to economic development. This enhances their visibility in the community and facilitates change of attitude.

Collective advocacy. Mutual interactions in the groups and subsequent cohesion built over time facilitate collective problem solving and advocacy for disability inclusion.

Enhance esteem. Participation in group activities often enhances members' esteem and self-actualization.

Widen economic opportunities. VSLAs increase opportunities for unemployed persons with disabilities to start businesses and other economic ventures.

Socio-economic support networks. VSLAs provide opportunities for persons with disabilities to participate and build socio-economic support networks.

VSLAs complementing Micro Finance Institutions (MFIs)

VSLAs operate complementary to MFIs, to serve people living in remote places whose income is low and irregular, who need to save cash in small amounts, and have limited demand for credit because markets for their products are weak. Such populations are costly for MFIs to serve. According to the World Report on Disability (2011), anecdotal evidence suggests that few persons with disabilities benefit from microfinance schemes because many have few assets to secure loans, and may have lived in poverty for years. Joining VSLAs can empower persons with disabilities to access mainstream economic opportunities. Through VSLAs, some community members may build up their assets to become attractive clients for MFIs, credit unions and banks. There is growing recognition of the importance of VSLAs as an entry-level component of a vibrant financial system.

However; MFIs have barriers that restrict persons with disabilities to access savings and loan services:

- MFIs have the tendency of primarily reaching urban-based established business people; hence excluding the poorer segment of the population including the majority of persons with disabilities who live in rural areas.
- MFIs require collateral and prefer providing larger loans with low risk; yet persons with disabilities live mostly in poverty and have few assets to use in securing loans.
- MFIs usually exclude funding of start-ups whose performance they cannot predict.
- MFIs often consider persons with disabilities not as credit worthy.
- Information on credit facilities in MFIs is often not provided in accessible formats such as Braille, large print, Sign Language and easy-to-read formats.

Over the last decades VSLAs have become wide spread in communities in Africa, Asia and Latin America where formal banking services are not well established. In just 25 years, approximately 750,000 Savings Groups have been established comprising of over 15 million members in 73 countries. Each savings group manages assets of about US$1,200 on average, providing access to livelihood opportunities for income generating activities, consumption, investment, and emergency needs of low-income households. The vast majority of these households constitute the informal economy. This low cost concept has a very high success and sustainability rate and is being supported by many donors such as Bill and Melinda Gates Foundation, MasterCard Foundation, Barclays Bank UK, USAID, UKAID, FSD Africa and CARE to mention but a few.

Examples of Livelihood Programmes Centred on VSLAs

The following examples of livelihood programmes underscore the importance of the VSLA approach. They were started in different countries of Africa with a membership dominance of persons with disabilities:

I) **Association for the Physically Disabled of Kenya (APDK) Micro Finance Programme Kenya**

This programme commenced in 1997 and operates in 8 regions of Kenya with 340 established groups and total membership of 7,200. The programme received a revolving fund of Euros 104,000 from donors while members accumulated savings of Euros 180,000. The programme has yielded several lessons:

-When groups were given grants, there was a 50% failure rate however, when group members were encouraged to collect and manage their own savings, high

loan repayments were realized and the interests earned on savings inspired growth.
- Membership contributions facilitate ownership and sustainability.
-Compulsory savings and group guarantee facilitate ownership and success of the groups.
-Developing clear governance structures, systems and providing support supervision are critical.
-Interest rates and fees charged should be determined in consideration of operational costs for sustainability.
- Notwithstanding these positive developments, the programme is reported to be challenged by high human resource and operational costs and over dependence on donor support which in a way compromises sustainability.

ii) **Savings Group Programme for Persons with Disabilities - Uganda**

In 2010, NUDIPU started a Savings Group Programme in seven districts of eastern Uganda with support from NAD. By December 2014 the programme covered 13 districts of the country, consisting of 922 groups with 27,011 members. These included 17,741 Women (66%) and 3,907 Youths aged 16-25 years (14.5%). The number of Persons with disabilities had reached 16,043(Physical - 8,408, visual – 2,388, hearing – 1,567 and others – 3,681). The number of Members who started Income Generating Activities had reached 10,941.

By 2018 the programme had expanded to over 1000 inclusive groups with 30,781 members, accumulating a savings portfolio of over $1.3 million. It had supported start-ups of 13,250 Income Generating Activities. The average rollout cost was $34 per member. Although groups apply the same principles as per the VSLA guidelines, they must have a 60% majority of members who are persons with disabilities. Other members include parents/guardians of children with disabilities and community members (or well-wishers) without disability, who must not exceed 15% of overall membership. NUDIPU envisaged that these groups would have an inclusive membership while ensuring that persons with disabilities retain management control of the groups.

The groups are formed through self-selection usually covering a geographical area. Members receive intensive training for a period of 4 to 6 weeks by the Field Promoters who are paid by NUDIPU. The Field Promoters ensure that the by-laws are adhered to, they monitor progress and assist with conflict resolution. Groups usually become self-managed after 6 to 9 months. On completion of the first cycle, groups usually operate independently.

The groups formulate by-laws to govern their operations, conduct and determine the interest charged for loans and fees. They are required to contribute towards the cost of the start-up kit, which includes a cash box with three locks, money bags and member pass books and an accounts ledger. Members buy shares weekly and can access loans after 6 weeks at an interest

rate of 1% per week. At the end of an agreed cycle the accumulated savings and interest earnings are shared out amongst the members in proportion to the shares held. Members can use savings to buy shares when they commence the new cycle. Each group also has a social fund, which provides members a basic form of insurance for emergency assistance or medical and funeral expenses.

The NUDIPU district office captures financial data, gender distribution and client default rates. The data is centrally processed and submitted for inclusion in the VSLAs global statistics.

Impact of the NUDIPU Savings group programme

- The NUDIPU Savings group programme has been rated as very successful due to its high level of ownership by people with disabilities and socio-economic benefits to the target group. The primary benefits have been income smoothing through improved household income, food security and increased resilience to business related and personal setbacks.
- The relatively low costs for training and start up, transparency and simple management principles have ensured a vast roll out.
- The fact that there are minimal overhead costs involved and members share out incomes generated through interest and fees, makes the scheme very attractive and creates an incentive to mobilize savings.
- There are minimal risks involved due to the group pressure, and subsequently write offs and default rates are very low. There is no need to attract external revolving or guarantee funds which allows quick replication and expansion.
- The program has ensured a greater level of inclusion of persons with disabilities in society since they have become more active as entrepreneurs who have earned the respect of community members and are no longer being viewed as dependent on charity.
- The level of self-confidence of group members has reportedly increased, which has had positive effects since some members have been elected into civic society and political positions.

The CBM Livelihood Advisor visited projects in Uganda and studied the VSLA/Savings group model and considered it as a suitable and viable strategy to achieve greater financial inclusion of persons with disabilities. Particularly in rural areas and informal settlements where most of the CBM target groups reside, this model was considered as a first stepping stone towards breaking the viscous cycle of disability and poverty.

iii) CBM- Funded VSLA Programme for NUDOR Rwanda

This commenced as a pilot programme between 2016 and 2017. With a budget of Euros 170,000, it reached 3,700 persons with disabilities and caregivers and contributed to economic empowerment of beneficiaries.

In view of the examples above, CBR/CBID programmes are instrumental in linking their beneficiaries or existing empowerment groups with the Savings groups. CBR/CBID personnel can serve as facilitators to support the establishment of savings groups and monitor group performance, document statistics and evaluate outcomes to inform improvement and replication.

Mainstreaming Disability in Financial Services: Lessons from Uganda

In Uganda, Rwanda and Ethiopia, the Norwegian Association of Disabled (NAD) and CBM have done a tremendous job lobbying the donor and international NGO community to include persons with disabilities in their programs as a target group.

Through funding from NAD, NUDIPU an umbrella organization of persons with disabilities in Uganda commenced a livelihood program in 2005 with the aim of lobbying Microfinance Institutions in Uganda to promote inclusion of persons with disabilities. The objective of the project was to increase the awareness level of mainstream microfinance service providers of persons with disabilities as potential clients, removal of barriers and inclusion in their programs as equal clients. NUDIPU also created awareness among persons with disabilities and their organizations on the services provided by microfinance institutions.

This program has increased the level of awareness and has resulted in removal of barriers and inclusion of more persons with disabilities in MFIs. However it was realized that MFIs mostly reached persons with disabilities in or near urban areas who already had established businesses. NUDIPU arrived at the conclusion that standard credit-led MFI approaches are unable to meet the needs for financial services of people with disabilities in rural areas because their need is not for debt-led financial services, but primarily for savings-led services. Due to high operational costs and location in urban areas, MFIs are either not accessible to the target group or services cannot be offered conveniently and competitively. This prompted NUDIPU to mobilize persons with disabilities at establish VSLAs. These have since grown strong and helped to empower persons with disabilities for economic independence.

Conclusion

VSLAs have proven to be a powerful tool and a first stepping stone towards financial inclusion of persons with disabilities who have often been left out of mainstream financial services. Apart from supporting development of disability specific savings and loan groups, CBM, NAD and other stakeholders promote inclusion of persons with disabilities in mainstream savings and loan groups and lobby local and international NGOs to include at least 5% persons with disabilities in their groups. This is a cost effective and sustainable approach and can reach significantly high numbers of persons with disabilities and assist them to break out of the vicious cycle of poverty and ensure equitable access to economic empowerment opportunities.

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Chapter 6

Self-Help Groups for Mobilizing Caregivers of Children with Disabilities in Kenya and Cameroon

Joseph Gona, Sally Hartley, Charles Newton, Pascal Ahidjo, Karen Bunning

Introduction

This chapter shares experiences of two projects that successfully improved well-being of persons with disabilities and their families through self-help group formation and support. One project was implemented in Kilifi in Kenya and the other one in Northern Cameroon. One key aspect of both projects was to document all major steps, processes, developments and experiences from inception to the end.

The Kilifi project was a relatively short term research project that lasted three years. In contrast, the Cameroon project was embedded in an ongoing CBR/CBID service programme, which had operated for over 13 years. The Cameroon interventions and evaluation processes were based on 'good practice' and as such were broader and less specific than those in the Kenyan research project. However, the Cameroon project had more participation of Organizations of Persons with Disabilities (OPDs) than in the Kenyan project. Nevertheless, the outcomes of both projects were positive and revolved around a stronger sense of self-esteem, increased sense of autonomy, increased level of involvement and greater shared experiences of persons with disabilities, carers and other actors.

Self-Help Groups

According to the CBR Guidelines, self-help groups are informal groups of people who come together to address their common problems (WHO, 2010).

While self-help might imply a focus on the individual, one essential characteristic of self-help groups is the idea of mutual support – people helping each other. These groups are sometimes known as peer groups, social groups, clubs or mutual aid groups.

Self-help groups are reported to be instrumental in poverty reduction (Tearfund, 2017) and in social development and economic empowerment (Cohen et al, 2012). They have successfully been employed in varied contexts including health care, rehabilitation (Cohen, Rajah & Underhill, 2012), education (UNESCO, 2015) and advocacy (Adams & Galvaan, 2016). When persons with disabilities participate in self-help groups, their visibility within their communities can improve (Gona et al, 2020). Membership can provide them with mutual support, encourage them to share resources and find solutions together. This improves their confidence and self-esteem. If nurtured well, self-help groups involving persons with disabilities and their families can help achieve many targets of CBR/CBID.

In many areas formation of self-help groups for caregivers of children with disabilities is a relatively new practice (Brody, de Hoop &Vojtkova, 2017). Caregivers, are often unpaid family members (parents, foster parents, grandparents or head of households, friends or neighbors) who provide care to individuals who have acute or chronic conditions and need assistance to manage a variety of tasks ranging from bathing to dressing, taking medication, eating, playing and learning. In the course of attending to the needs of children with disabilities, caregivers often face several challenges themselves including non-acceptance, lack of public awareness, stigma, embarrassment, inadequate social services as well as psychological challenges (Ndirangu and Midigo, 2018). Overcoming these challenges is vital if caregivers are to be successful and achieve their goal of maximizing the quality of life of their family member and indeed of the whole family.

Persons with disabilities and their carers are considered and are usually among the poorest of the poor. To address this, caregivers of children with disabilities were encouraged to form self-help groups which offer a pathway of opportunity to improve their own situations, both economically and socially and to take control of their lives and to improve the quality of life of their children.

The Kilifi Caregiver Self-help Project

The Kilifi self-help groups started in 2016. Deliberate effort was made to document every major step and development. Two groups of caregivers were mobilised in each of the 10 sub-locations across Kilifi County. Inclusion criteria in the self-help groups was having a child with disability, willingness to participate and one's availability to attend meetings. Each member signed a consent form. The caregivers were mobilized for planning meetings to among others select leaders (Chair and Vice Chair, Secretary and Vice Secretary, and Treasurer), make decisions on size of membership, frequency and location of meetings, group identity and name.

A team of facilitators identified to build the capacity of the groups in group management, livelihood development and self-advocacy. Besides training, the facilitators engaged in regular monitoring for support supervision and coordinated intergroup sharing for collective learning.

In the Kilifi project, caregivers shared challenges of bringing up children with disabilities. The caregivers got opportunities for economic empowerment and, received support relating to education, health and rehabilitation. The project initially focused on economic empowerment as this was viewed as an essential first step. Simple and affordable income generating activities were undertaken. For example, some groups started by making thatching material and liquid soap for sale, while others engaged in agricultural production (livestock and crop growing) and some engaged in general merchandise. This improved the

groups' earnings and savings, peer sharing of experiences, cohesion and trust, which empowered member. Subsequently, the groups were able to undertake formal registration and opened bank accounts since they were now credit worthy.

Kilifi Project Outcomes

Before the project, the caregivers were weighed down by 'burden' of caregiving experienced on a daily basis. They talked of feeling lonely with their troubles and lacking support both within and outside of the family. Many experienced stigma in their communities, which was associated with feelings of sadness.

> *"I have to carry the child and do everything as if people are not seeing what I'm going through. Even when I sit and chat with them, I always feel lonely as I know duties are waiting for me to care for the child",* said one mother.

After the project intervention, there was a much stronger sense among caregivers of being and working together. Related to this was their development of skills in problem-solving and in helping each other. There was a general view that times were easier and that their lives had improved because of their participation in the self-help groups.

> *'…..we sat together and found ways and means of how we could help each other... If we don't (visit) we use mobile phones… my child has this and this. We call each other and visit the child. We discuss what we could do",* said another mother.

There were examples of increased peer support amongst the members. This was evident through assistance in building houses for members who had poor houses or those whose houses were destroyed by fire.

> *"It is the unity of the group. Every Tuesday we meet here to see how we could make better our lives",* said a father.

In terms of education, caregivers demanded that educational services for children with disabilities be accessible within their communities. This was shown through requests for educational assessment teachers to visit groups and assess children with disabilities for school placement.

In regard to health services, some groups asked for physiotherapists to train them in basic physiotherapy skills so that they help their children at home.

> "*The exercises for our children are far in hospitals. When we had some training in helping to exercise our children, we saved time of travel and have been able to do a number of things at home and in the community. We have some of these activities as a group and learn from each other", said* a mother of a child with multiple disabilities.

Some groups accessed and benefited from bank loans.

> *"We got a loan from our bank and use it in the group business. When we sit we plan our business, how is it progressing; if certain items are finished, we plan and then get more items for sale. Whatever we get, we send it to the bank",* said a group treasurer.

The Self-help Project in Northern Cameroon

One of the priorities of the Comprehensive CBR North Cameroon Program (PIAP) implemented by Codas Caritas Garoua was to support the setting up of Parent's Self Help Groups in Northern Cameroon using the existing CBR/CBID fieldworkers.

The implementation of this support began in 2006. The objective of the intervention was to encourage the creation of Organisations of Persons with Disabilities (OPDs) who would then be empowered to spearhead community mobilization and advocacy for disability inclusion (Messi, 2017). OPDs support capacity building of persons with disabilities by providing them with a common

platform to share experiences and build a common discourse. Generally, these organisations provide their members with information on disability (regarding their rights, existing provisions and services) or offer services such as sign language training and advocacy among others.

In the Northern Cameroon project CBR/CBID fieldworkers were trained in facilitation and community mobilization techniques. Using these skills, they identified several informal groups formed by parents of children with disabilities at village level. These groups defined their membership to include persons with disabilities and parents of children with disabilities. Other inclusion criteria differed from one group to another but for most groups' criteria included being a resident of the village, paying membership fees and commitment to respect all group rules and regulations. Parents' self-help groups started by setting goals for themselves.

The CBR/CBID fieldworkers assisted the groups to improve implementation of operating procedures of their respective groups. They also provided training in leadership, group dynamics and management of the self-help groups. In addition, they monitored the groups and offered supervision. The parents whose children had earlier benefited from the program's interventions helped to bridge the CBR/CBID fieldworkers and other caregivers. These parents visited other caregivers and shared knowledge and skills to support children with disabilities. During the home visits, they mobilized other parents of children with disabilities and invited them for meetings. During the meetings, the parents shared experiences relating to caring for children with different disabilities and the challenges experienced. Parents also engaged in various livelihood improvement projects including group savings.

Northern Cameroon Project Outcomes

During the thirteen years of implementation, 52 parents support groups were set up. In these groups, peer interaction and shared learning enhanced group cohesion, improved individual members' esteem and participation and

enhanced self-advocacy. Over the years of project implementation, the groups grew their own savings and gradually became less dependent on CBR/CBID fieldworkers to sustain livelihood.

Lessons learnt

For self-help groups to function well, there is need to identify common interests, promote peer sharing and active participation by all members, invest in group governance, define operational procedures and ensure regular support supervision.

To promote participation and inclusion, there is need to plan with consideration of accessibility provisions, members' schedules and routines, expectations as well as gender roles and responsibilities.

To ensure sustainability of the self-help groups, individual contributions facilitate ownership. There is also need for transparency and accountability, effective leadership and management of the group as well as its resources.

Conclusion

Self Help Groups are instrumental for empowerment of vulnerable individuals especially in limited resource settings. They have potential of transforming wellbeing of persons with disabilities and their caregivers. CBR/CBID fieldworkers and organizations of and for persons with disabilities play a vital role in facilitating the establishment of such groups and providing support supervision. Self-help groups should therefore be promoted to ensure participation and inclusion of persons with disabilities and other vulnerable individuals in socio-economic development.

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Chapter 7

Community Based Rehabilitation and Disability Inclusive Disaster Management

Simon Munde, Carolyne Maholo Sserunkuma, Moses Ddamulira,

Introduction

Many countries worldwide continually experience disaster due to climate change and other challenges. Persons with disabilities are highly prone to disaster due to impairment and barriers they experience in society. Despite existence of various policies to promote participation and inclusion of persons with disabilities, they are often excluded from disaster management programs. The Sendai Framework advocates for substantial reduction of disaster risk and loss of lives, livelihoods, social, economic, physical, cultural and environmental assets (*UNODRR*, 2015). Disability inclusion and disaster risk reduction are both highlighted in the Sustainable Development Goals (SDGs). Engendered needs identification and deliberate investment in disability inclusive disaster management is instrumental for the realization of the SDGs and the Sendai Framework.

Community Based Rehabilitation: An Overview

Community Based Rehabilitation (CBR) was initiated by World Health Organization (WHO) following the Alma-Ata declaration in 1978 to increase access to rehabilitation services in communities. It refers to measures undertaken to empower persons with disabilities and create an enabling environment to ensure their participation and inclusion at individual, family and community level. CBR is currently appreciated as an effective *strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, social justice, livelihood, vocational, social and other services"*

CBR encourages the use of a twin-track approach for disability inclusive development. The approach involves interventions to empower persons with disabilities based on their capacity needs and creating an enabling environment at family and community levels at the same time.

Persons with Disabilities and Disaster Risk

According to the 2011 World Report on Disability, persons with disabilities account for 15% of the world population. Persons with disabilities are individuals with long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UN, 2006).
United Nations defines disaster as a serious disruption in the functioning of a society, which results into widespread human, material, economic or environmental effects to the extent that the affected individuals or community cannot manage using their own resources (UNISDR, 2009). Disaster arises from a hazard which refers to anything that has potential to cause harm. Disaster only occurs when a hazard is combined with vulnerability which implies limited capacity to identify, detect, prevent or mitigate its occurrence.

Vulnerability is a state of being prone to or most likely to experience harm. It is often assessed in reference to individual, group or community potentials sometimes determined by age, sex, location and timing in relation to a hazard. In many cases, persons with disabilities are disproportionately more at a risk than their non-disabled counterparts. One's inability to see, move, hear, communicate or grasp things easily, makes them highly vulnerable to disaster. For instance infants and children with severe disability or those who may be living at home due to lack of rehabilitation and are usually at home are prone to burns and other hazards which occur within the home setting. Children of school going age are usually moving about in the community as they go to or return from school. They are therefore most likely to be affected by a hazard that may occur on the road or anywhere in the community. Children with hearing impairment are more prone to traffic accidents because they may miss the hoot of a car while people with movement challenges are more vulnerable during floods. During a flood, a person with a physical disability with or without a mobility aid experiences difficulty in escaping the flood and can easily be left behind. The same may happen during landslides as people run to safety. Likewise, a deaf person may suffer the same fate since he/she will not heed to warning sounds during a landslide. In case a building collapses or catches fire, a person with visual impairment in the building may fail to safely escape due to limited orientation and mobility skills and lack of training in evacuation procedures and route. It is very possible that on hearing the fire alarm, a person with visual impairment runs towards danger instead of going to safety.

Despite being among the most vulnerable individuals in society, persons with disabilities are hardly provided for in disaster management. Considering their various needs and the scarcity of resources in many communities especially in developing countries, CBR can be utilized to empower persons with disabilities and facilitate disability inclusion in disaster management.

Experiences of Floods in Communities

Disasters have been reported in rural and urban communities alike. They result from interaction between a hazard and vulnerability. In many communities, disaster arises from hazards often caused by human activities.



Pic 1: Flooding in a slum located in one of the suburb in Central Uganda. Pic 2: Floods in a rural community of Eastern Uganda. Pic 3: A road cut off by floods in Eastern Uganda (courtesy of Uganda media)

Pic 4: Residents of Kasika Village in Rukoki Sub-county Kasese District, still pondering on what to do next after houses had been washed away.

As observed, land reclamation, poor waste management and many other human activities increase the likelihood of disasters. Agricultural activities are among the common human practices that contribute to disasters in rural communities. Many people cut trees to expand land to increase production of food and cash crops forgetting that trees provide windbreaks and facilitate rain production. Poor farming methods and pollution are common in all communities. Most African countries are agro-based. In Sub-Saharan Africa, approximately 23% of countries' GDP is realized from agricultural production with 70% of the population operating small hold farms AGRA. (2017). In Malawi and many other African countries, 80% of the population is agro-based and lives in rural areas. Poor land management causes a decline in agricultural production leading to increased food insecurity and many other social and health hazards.

Pollution is yet another hazard that poses risk to populations. It comes in different forms including household pollution, poor waste management and industrial pollution. As economies encourage industrial development, environmental protection policies ought to emphasis the sustainable

development dimension. With increased rain, poor waste management in communities, silting and landslides, floods are common in some communities. In 2015, Malawi experienced extreme rainfall that culminated into floods which displaced over 638,000 people (116, 000 households) in 15 districts across the country. Persons with disabilities were among those affected by the floods however, they missed out in most interventions. Although several stakeholders rushed in to intervene and provide humanitarian support, they hardly knew how to ensure inclusion of persons with disabilities. They reported lack of knowledge and information on the needs of persons with the different disabilities. To bridge the gap Malawi Council for the handicapped, (MACOHA) came in to implement community-based interventions. They engaged stakeholders to empower persons with disabilities and mitigate barriers to their participation which helped to enhance resilience and facilitate disability inclusion.

Disaster Risk and Vulnerability of a Child with Disability in Kanyaruboga

In Kanyaruboga village Kasese district a flood prone community in Western Uganda; a 15yr old girl, Mbambu "not real name" has severe movement challenges due to cerebral palsy. She is a first born and has three siblings but because of her condition, she is always left indoors.

> *"….in the past it was easy for me to carry her around but now that she is all grown and heavy, I cannot carry her wherever I go." Says the mother.*
>
> *"Mbambu fell sick when she was 6yrs old. She was already in school and doing well but she suffered from diarrhea and vomiting with a very high fever. We did all we could to treat her but later realized that she could not move her hands and legs. We have done everything but nothing helps".*

Located in a rural setting, Mbambu's family operates a small farmland. Most of the land and livestock were sold off to improve her condition but all in vain. The father now blames Mbambu and her condition for making them poor. Two of Mbambu's siblings attend a neighbourhood universal primary school while the youngest always goes out with the mother during her errands. Whenever she is not working on her farmland, Mbambu's mother engages in casual labour. She sometimes works on people's farms.

Because Mbambu neither sits nor moves on her own, the mother leaves her home. She is usually locked up in grass thatched house constructed with mud and reeds. Her home is located in a low land highly prone to floods.

With climate change, Kasese district is one of the districts most affected by prolonged dry spells with occasional wild fires, living in a grass thatched house makes the home equally prone to fire.

How can little Mbambu escape the collapsing walls of this building on a rainy day?

And the wild fire?

In such a case, the multi-sectoral interventions CBR could be of great help.

Disaster Management and Disability Inclusion

Disaster management refers to planning, application and organization of interventions to prepare for, respond to and recover from disasters. It aims at reducing or avoiding the potential losses due to hazards, ensuring prompt and

appropriate assistance to victims of disasters and realizing effective recovery. It is all about identifying and filling capacity gaps. This may be guided by the disaster management cycle:

Fig 1: Disaster management cycle

Like all cycles, the disaster management cycle presents a continuous process of planning to prevent or mitigate disasters, reduce the impact of disasters and guide interventions during the disaster and throughout recovery period. All the five phases are equally important. The process involves needs identification, vulnerability assessment and capacity assessment at each phase.

Specific capacity is required for identification and detection of the hazard to inform prevention, mitigation and preparedness. Hazards vary by nature, magnitude and causal factors. Much as some may be preventable, others can only be mitigated while for some, all we need is preparedness to mitigate them or their effects, cope with or manage with their occurrence. Identifying individual, family and community needs together with risk and vulnerability assessment help to inform effective planning and appropriate targeting of intervention. Most disasters can be prevented when individuals and communities are empowered to repel or manage throughout the disaster situation and the recovery period. When disaster strikes, disaster response to support the affected individuals and families to cope with, manage and recover is required. Persons with disabilities being part of the affected communities have specific needs which need to be addressed for them to access and benefit from such support.

Based on the nature of disability, their specific needs and level of empowerment, persons with disabilities are more likely to be excluded from development programmes including disaster and risk management interventions. . Many persons with disabilities miss out on provision of basic social services such as health, education and employment among others which increase their vulnerability hence increasing their risk to various hazards. Exclusion of persons with disabilities often arises from their impairments and the barriers that exist in society. One's inability see, hear, speak, walk, move

different parts of the body, perceive and interpret situations brings about specific needs. Identification of such needs and appropriate interventions to empower persons with disabilities helps to mitigate their vulnerability. However, this ought to be complemented with mitigation of barriers to participation such as attitude change, architectural and environmental modifications, appropriate communication provisions with pictorial, sign and tactile language, inclusive policy and practice among others.

While the Sendai Framework focuses on the adoption of measures for disaster management, the SDGs aspire to leave no one behind hence inclusion. Because of varying unique needs, persons with disabilities are among the most excluded individuals in society. It is therefore important for deliberate effort to be investing in ensuring their access and benefit from all services and opportunities in society evident with active participation and inclusion hence disability inclusion. United Nations defines disability inclusion as *"meaningful participation of persons with disabilities in all their diversity, promotion and mainstreaming of their rights, development of disability-specific programs and consideration of disability-related perspectives, in compliance with the Convention on the Rights of Persons with Disabilities (UNCRPD)"*[1]. It is where deliberate effort is made to identify the needs of persons with disabilities, empower them and create an enabling environment for them to actively participate in all aspects at individual, family and community level. Disability inclusion is affirmed by the SDGs which clearly emphasize inclusion in all sectors including disaster management.

As hinted earlier, disability inclusive disaster management starts with engendered needs identification of persons with different disabilities. Output of which is utilized for effective planning and intervention for capacity development and appropriate modification to promote their participation and inclusion throughout the management cycle. It is therefore important for stakeholders to develop appropriate strategies for disability inclusive disaster management.

Disability Inclusive Disaster Management

a) Experiences from Uganda

Kasese is one of the most disaster prone districts in Uganda. The area experiences prolonged dry spells with occasional wild fires, part of it is prone to landslides while the other experiences floods during rainy seasons. In such a setting, multi-sectoral collaboration and intervention is essential not only for

disaster management but also disability inclusion and sustainable development.

In this regard, the National Union of Disabled Persons of Uganda (NUDIPU) has been implementing a disability inclusive disaster risk reduction project in Kasese and Bududa districts with support from the Norwegian Association of the Disabled (NAD). The project works with communities, civil society organizations and government departments to promote disability inclusive disability inclusive disaster management. Through their efforts, persons with disabilities have been nominated on disaster management committees at district, municipality and sub-county levels. Disability inclusion is now prioritized by many stakeholders in risk management, humanitarian support and inclusive development efforts.

b) Experiences from Malawi
During the 2015 floods in Malawi which affected over 15 districts, MACOHA and the Federation of Disability Organisations in Malawi (FEDOMA) worked with other stakeholders to promote disability inclusion in disaster response.
They specifically worked in the districts of Nsanje, Chikwawa, Phalombe and Mulanje in Southern Malawi which they assessed to obtain disaggregated data on disability and aging as well as humanitarian agencies providing services.

Using the CBR approach, persons with disabilities were identified and empowered to become independent so as to access basic needs in equitable and dignified ways. In addition, humanitarian service providers were oriented on the needs for the various categories of disability and the barriers to participation to facilitate disability inclusive service delivery. MACOHA specifically provided guidance to ensure appropriate accessibility modifications especially for the communal latrines and water points. In these facilities; ramps, rails and wide entrances were constructed to ensure access and effective utilization by persons with movement challenges, elderly, expectant mothers and children while landmarks were provided to enhance access for persons with visual impairments. For effective communication, the program worked with organizations of persons with disabilities (OPDs) for capacity development in sign language, provision of assistive devices, mobility training, hearing and visual aids and mental health services. A harmonized referral system was used. For continuity, persons with disabilities through their OPDs have successfully lobbied for their inclusion in disaster management at the district, area and village levels to ensure that they are part of the decision making processes.

Conclusion

CBR has been implemented in many developing countries to improve welbeing of persons with disabilities. It harnesses existing knowledge for shared learning, emphasises use of locally available resources which makes interventions affordable, acceptable and sustainable.

The unique and varying needs of persons with disabilities render them highly prone to disaster and yet are hardly provided for in disaster management. In line with the Sendai Framework, effective disaster management calls for needs identification and capacity development of persons with disabilities, their families and communities at different levels of the management cycle. CBR provides an opportunity for empowerment of persons with disabilities and creates an enabling environment for their participation and inclusion within their families and communities. It is therefore a great tool for disability inclusion, resilience building and sustainable development.

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Chapter 8

Key resolutions from the 6th CBR Africa Conference

Introduction

The sixth CBR Africa conference held at Intercontinental Hotel, Lusaka, Zambia in May 2018 brought together 542 participants from 45 countries to reflect on the theme*: "CBR for Resilience Building and Sustainable Development: Leave No One Behind."*The aim of the conference was to share knowledge, information and experiences for learning to improve service delivery and facilitate advocacy for effective disability inclusion.

In the last sessions of the conference, the participants approved the new constitution of CAN, which was written in 2016 to conform to Uganda Revenue Authority requirements and to change status from registration as a limited company. The participants also elected a new CAN Executive Committee and made resolutions for implementation going forward.

Conference resolutions

1. Persons with disabilities and their organisations should be involved in planning, implementation and evaluation of government programmes at all levels.
2. Efforts should be taken to ensure participation of persons with disabilities in the family and all sectors of the community.
3. There should be economic empowerment of persons with disabilities as a contribution to community based inclusive development through Self Help Groups.
4. The education and training of rehabilitation personnel should be carried out in Africa using standardized curricula to facilitate effective community based inclusive development.

5. Countries in Africa should move away from CBR to CBID as the latter will be more effective with guarantees of capacity development and addressing funding gaps.
6. Community based rehabilitation /community based inclusive development practitioners should involve persons with disabilities in all decisions that concern them (the latter).
7. In all African countries, all policy documents should be made available in accessible formats for all persons with disabilities for effective awareness creation and advocacy.
8. Action research should be promoted to provide empirical evidence on the effectiveness of community-based rehabilitation intentions for effective development initiatives.
9. There is urgent need for the domestication of The African Charter and Protocol on Disability, which is Africa's own context policy.
10. Data on gender and disability should be disaggregated for better profiling of persons with disabilities for effective service provision.
11. Working relations/partnerships should be built among CSOs, OPDs and governments through sharing of responsibilities to reduce vulnerability of persons with disabilities during service delivery.
12. Disability Focal Point Persons (FPPs) must be senior government officials who fully understand their role and are capable of taking forward issues pertaining to persons with disabilities.
13. Advocacy by OPDs should focus on existing legal systems backed by relevant Statutory Instruments.

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This book is s product of a successful 6th CBR Africa conference organized and hosted by a dedicated team in Zambia working together with government to plan and host this memorable event. The entire management team of CBR Africa Network appreciates the commitment exhibited for the successful conference.

The event brought together leading CBR professionals and practitioners, policy makers, service providers, persons with disabilities and parents of children with disabilities from different parts of Africa and beyond. The knowledge, information and experiences shared provided great learning and has informed the details shared in this book.

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