

CBR Guidelines: A Bridge to Inclusive Society Beyond the 2015 Development Framework



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Lead Editor



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Forewords

A Word from the Chair of CBR Africa Network (CAN)

I am happy to release the book of the Fifth CBR (Community-Based Rehabilitation) Africa Conference held from the 1st to the 5th of June 2015 in Nairobi, Kenya under the Theme “A Bridge to Inclusive Society beyond the 2015 Development Framework”.

This book is a publication of CBR Africa Network (CAN), the aim of which is to share the knowledge and ideas discussed at the conference. It is also the very first CAN book to be published in Africa entirely by Africans.

Originally scheduled to be held in Egypt, the Conference was moved to Kenya following unrest in North Africa. An outbreak of Ebola also resulted in a postponement of the Conference from 2014 to 2015. In spite of these challenges, CAN and its partners were able to plan and host a memorable conference that achieved its objectives. It helped the CBR sector to share learning, develop partnerships, and agree on 12 resolutions relating to CBR/CBID.

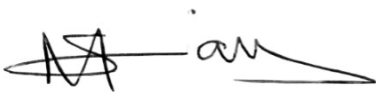
The event, which was held at the Kenyatta International Conference Centre, was an important occasion in the CBR calendar, bringing together more than 135 participants (42% women and 56% men) from over 24 countries.

This was the first CAN Conference since the launch of the CBR Guidelines at the Conference in Nigeria in 2010, and it represented an important opportunity for CBR stakeholders to come together to review progress against the Guidelines in the context of the broader development environment. As highlighted in Chapter 1 of the book, the CBR Guidelines are expected to inform planning, implementation and validation of programmes to enhance the lives of persons with disabilities.

What makes CAN events unique is the great variety of people who attend and present at the Conference. They have in common a passion for CBR/CBID and the Conference presents an opportunity to bring all of their knowledge and experiences together under one roof for the benefit of moving forward the CBR sector. Journeying through the 10 chapters of this book exposes you to a

rich variety of experiences; how persons with disabilities can be included in employment by improving communication and physical accessibility as well as removing barriers to financial inclusion, designing disability-inclusive disaster risk reduction strategies, how to use CBR to make education inclusive for all children with disabilities, and explaining the complementary roles of government and NGOs in implementing CBR programmes.

At the fifth CBR Africa Conference I had the great honour of being elected Chairperson of CAN and I look forward to serving CAN over the coming years. I hope that you enjoy this book and encourage you to continue sharing your knowledge, wisdom and ideas through the CAN network for the benefit of all people working in this critical and dynamic field.

A handwritten signature in black ink, appearing to read 'Musonda Siame', with a long horizontal line extending to the right.

Musonda Siame
Chairman, CAN Executive Committee
E-mail: musonda@afri-can.org

A Word from the Chair of the Conference Planning Committee

Towards the end of 2013 I met with representatives of CBR Africa Network (CAN) and learned of the difficulties they were facing regarding organization of the 5th CBR Conference. Egypt was the planned location for the conference but the challenges of unrest in North Africa were making this complicated. Kenya had been identified as an alternative location following the country's bid to hold the Conference at the 2010 Conference in Nigeria. I was asked to assist in making a request to the Government of Kenya to agree to host the Conference and to lead the mobilization of stakeholders. Although time was short, the response both from Government and stakeholders was positive. Government committed to supporting the Conference and requested us to work closely with the National Council for Persons with Disabilities (NCPWD).

By January 2014, we had formed a Committee comprising more than 20 stakeholders including representatives of both Civil Society and the Government. NCPWD, a semi-autonomous Government Agency, was well represented in the Committee and a person delegated by the Principal Secretary represented the Ministry responsible for disability. The Association of the Physically Disabled of Kenya (APDK), a major CBR stakeholder, agreed to host the Secretariat of the conference. I was elected Chairman of the organizing Committee. We nominated four subcommittees to carry out respective roles and decided that the Conference would take place in November 2014. However, the outbreak of Ebola in West Africa caused a travel ban across the region and yet we needed representation from West Africa. The Chairman of CAN at the time was from West Africa. We agreed to postpone the conference to June 2015. Despite this challenge and fundraising difficulties owing to the short time available, I am proud that we were able to organise a successful Conference.

The Conference highlighted positive developments, good practices and lessons learned in the implementation of the WHO CBR Guidelines as well as stimulated debate, explored solutions to identify gaps, and for promoting replication and scaling up of successful interventions in CBR. A common theme of our discussions was the achievement of a Post-2015 Disability- Inclusive Development Agenda. The programme was developed in partnership with members of the Conference committee, the CAN Executive Committee (EC) and CAN Secretariat. As is usual

with CBR Africa Conferences, our aim was to give opportunities to a broad range of speakers and to cover a wide range of CBR themes.

Vital to note is that the CAN general meeting was held on the sidelines of the Fifth CBR Africa Conference, divided into sessions over the different Conference days. The history, goal and mission of CAN were presented; and proposals for amendment to the CAN Constitution were presented, discussed and passed. This was followed by reading and adopting the Chairman's and Treasurer's reports. Then each country and region was given time to discuss their nominations to the CAN Executive Committee. A new EC was elected with fair regional representation, that is; Burkina Faso, Cameroon, Egypt, Kenya, Tanzania, Uganda and Zambia.

A formal hand-over to the new EC was performed in the presence of the general assembly; and the new EC held its first meeting shortly after the elections at the Kenyatta International Conference Centre in Nairobi.

Dr Samuel Kabue

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Ecumenical Disability Advocates Network**

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CHAPTER 1

Community Based Rehabilitation (CBR) Guidelines and Sustainable Development Goals

Steven Msowoya, Zamo Soumana***

Summary

The WHO CBR Guidelines remain a valuable framework for mainstreaming disability at various levels of national development. They continue to serve as one of the key instruments for implementing the UNCRPD and other legal instruments especially where the Guidelines are backed by enabling policies, strategies and legislation. On the other hand, shortfalls in the design, scope and presentation arrangements of the Guidelines present a challenge in terms of understanding the meaning and application of the concepts of rehabilitation, empowerment and social inclusion. Similarly, the exclusion of strategies for capacity building of CBR cadres and of globally acceptable tools for assessing the impact of CBR on the lives of persons with disabilities and their families are some of the areas that may need to be revisited if the Guidelines are to serve as a globally acceptable development framework for realization of the Sustainable Development Goals.

Introduction

CBR has been defined as a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities (ILO, UNESCO, WHO, 2004). It is a rights-based and development oriented approach/strategy for promoting inclusive development. CBR focuses on enhancing the quality of life of disabled people and their families; meeting their basic needs and ensuring inclusion and participation in their communities. It has a multi-sectoral design with five interrelated components, namely, health, education, livelihood, social and empowerment. These components and their respective elements form the CBR matrix of CBR Guidelines (WHO, 2010).

CBR represents specific time-limited, planned processes in which families, local communities and persons with disabilities work together to achieve the best possible level of ability for functioning, independence and social participation.¹ The strategy has been embraced by more than ninety developing countries to promote mainstreaming of disability in development endeavors both at national and community level.

Largely based on presentations at the 2015 CAN Conference, this paper discusses the extent to which CBR Guidelines remain relevant in promoting empowerment of persons with disabilities, their families and community in light of the adoption of the 2030 Global Development Agenda (GDA). It examines the strengths and gaps in the Guidelines, reflects on the application of the concepts of rehabilitation, empowerment and inclusion and makes recommendations for improvement of the Guidelines.

CBR Guidelines: Strength and Gaps

CBR guidelines were developed by stakeholders in the CBR and disability fraternity from different parts of the world with support from World Health Organization (WHO). Launched in Abuja in 2010, the Guidelines are expected to inform planning, implementation and validation of programmes to enhance the lives of persons with disabilities. Considering the dynamic environment in which we operate it is important to have them analyzed to maintain relevance in the global arena.

Strengths of the CBR Guidelines

Implementation of CBR Guidelines provides measures for equipping persons with disabilities with skills and competencies to integrate into society, and to

1 The ten key CBR ingredients for Africa as agreed at the first CBR Africa Network Conference are as follows: CBR must take a rights-based approach, empowering disabled people and their families; CBR must involve disabled people, parents and their organisations from the start; CBR must enable key stakeholders to access information on all issues, including HIV/ AIDS; CBR must be holistic; it must look at people with disabilities in totality; CBR must advocate for appropriate legislation and policies; CBR must enhance self-advocacy of disabled persons; CBR must develop long term and short-term plans together with all stakeholders. It must 'be strategic'; CBR must ensure inclusion of disability issues in all development programmes. It must collaborate with all sectors; CBR must take into consideration local cultures, resources and practices; CBR must address issues of poverty among disabled people and their families (Source: CAN (2003). CBR: A Participatory Strategy for Africa. Page 199)

participate and contribute to the life of their families and communities. CBR therefore facilitates acceptance of persons with disabilities in society, contributes to the equalization of opportunities, realization of economic development and poverty reduction. CBR Guidelines facilitate a significant shift from the charity medical model to the social and human rights perspective, hence it is considered essential for implementing the UN Convention on the Rights of Disabled People (UNCRDP).

By focusing on social inclusion, access to basic services, economic development and poverty reduction, CBR Guidelines promote social justice and improved livelihood for persons with disabilities and their families. Further, like the Sustainable Development Goals, the five components of the CBR matrix are integrated and indivisible thereby providing flexibility in application (UN, 2015) This means that implementers of CBR programmes can decide to develop monitoring frameworks (targets and indicators) for a mix of selected components and elements that in their view best address their specific needs and context.

CBR Guidelines inform effective programme implementation especially when supported by enabling policies, strategies and legislation at all levels. In this way, implementation of the Guidelines challenge national governments to review and or develop policies, programmes and legislation and allocate appropriate resources thereby creating an enabling environment for disability inclusive development across sectors and for the attainment of the Sustainable Development Goals (SDGs): “leave no one behind”.

Gaps in the CBR Guidelines

Notwithstanding the cited strengths, the CBR Guidelines have a number of inherent weaknesses that CBR practitioners and researchers may need to consider as they review the current Guidelines.

Much as the CBR matrix presents a comprehensive range of areas (components and elements) to inform development of intervention, the Guidelines lack clarity on the place of ‘Empowerment’ in CBR. While empowerment is the ultimate objective of CBR, the Guidelines through the CBR matrix present empowerment solely as one of the components with elements that promote active participation and self-representation by persons with disabilities. Empowerment as a result is not highlighted within the structure of the matrix. Similarly, while linkages among components of the matrix are clearly indicated in the matrix, the same

is not the case for linkages and interrelationship among elements in the matrix. This poses a challenge to implementing measures for networking/coordinating within CBR.

The term rehabilitation, as presented in the CBR Guidelines, no longer simply refers to individual medical treatments but rather to a holistic system of services and activities aimed at addressing psycho-social needs and the general well-being of the individual using a wide range of sectors (NAD, 2010). Use of the term rehabilitation in CBR, as well as presentation of rehabilitation as an element under the health component of the CBR Matrix could imply that CBR has a health/medical orientation.

Effort has been made to develop indicators that CBR practitioners and researchers can use to capture positive change that persons with disabilities may experience as a result of benefitting from CBR (WHO, 2015). Given that similar efforts to develop tools for assessing the impact of CBR initiatives are currently underway (Wickeden et al, 2016), the CBR Guidelines are not accompanied by a universally acceptable, comprehensive and participatory tool kit that can be used by CBR stakeholders to assess capacity and effectiveness of delivery mechanisms and impact. This makes comparison and learning from between/among CBR programmes rather difficult.

Lastly, the Guidelines do not prioritize issues of capacity building for generation, management and use of reliable, quality and segregated data that could be used both as a baseline for programme planning and monitoring as well as to inform policy.

Remaining Relevant: Inclusion Vs Rehabilitation

Shafik Asante (Cited in Dube, 2015) in her discourse on inclusion states:

“It is time we recognize and accept that we are all born “in”! ... No one has the right to invite others in! ... It definitely becomes our responsibility as a society to remove all barriers which uphold exclusion since none of us have the authority to “invite” others “in”!

Based on Asante’s premise, inclusive development could be defined as deliberate efforts to establish and operationalize enabling legislation, policies and systems that respond to diverse abilities, needs and aspirations of all citizens irrespective of their specific conditions. This is corroborated by others who have defined Disability Inclusive Development (DID) as a process that *‘respects the diversity*

that disability brings, appreciates disability as an everyday part of the human experience, sets out to achieve equality of human rights for PWDs and aims for full participation in, and access to, all aspects of society’ (CBM, 2012).

Inclusion adopts a twin track approach, namely, through mainstreaming by engaging the society to remove the barriers that exclude persons with disability as well as targeting individual or groups of persons that are excluded, through building their capacity and supporting them to lobby for their inclusion. Inclusion should therefore be understood both as a process and a result.

On the other hand, like mainstreaming, rehabilitation as a concept within CBR describes ‘processes’ as opposed to a result of the various CBR interventions. The concept has evolved from (initially) referring to medical treatments and related intervention to a process that involves implementation of a range of coordinated interventions across education, health, social and livelihoods sectors to promote equalization of opportunities, active participation and social inclusion for persons with disabilities. This development notwithstanding, authoritative literature on the subject tends to largely limit the concept of rehabilitation to the provision of health oriented interventions. For example, The World Health Organization in presenting the benefits of rehabilitation services documents that ‘*Access to rehabilitation can decrease the consequences of disease or injury, improve health and quality of life and reduce the use of health services’* (WHO, 2014). While CBR remains a viable tool for promoting disability inclusive development, there is need for on-going debate to review the meaning and application of the concept of ‘rehabilitation’ and to possibly replace it with a more relevant term such as inclusion (I) thereby necessitating a change in terminology from CBR to Community Based Inclusive Development (CBID).

Ensuring Universal Application of the SDGs

The Global Development Agenda adopted in September 2015 has 17 sustainable development Goals (SDGs) five of which have disability specific targets and

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- 2 These are Goal 4: Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all; Goal 8: Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all; Goal 10: Reduce inequality within and among countries; Goal 11: Make cities and human settlements inclusive, safe, resilient and sustainable and Goal 17: Strengthen the means of implementation and revitalize the Global Partnership for Sustainable Development (Source: United Nations. (2015). Transforming our World: The 2030 Agenda for Sustainable Development A/RES/70/1)

indicators.² The agenda is well poised to inform national governments on matters of promoting DID through their respective poverty reduction or growth and development strategies. However, unless UN member states commit to use SDGs to inform development of their respective national development strategies, it is likely to remain a challenge to wholesomely mainstream disability issues through CBR.

A positive stride in this area would require that UN member states align disability specific indicators and targets in the SDG with corresponding indicators and targets in national development programmes on the one hand, and those in national development programmes with corresponding indicators and targets in CBR, on the other. Towards the same end, countries would also need to develop disability specific indicators and targets for the other 12 SDGs and likewise align them with targets and indicators in national development programmes and CBR.

CBR Guidelines should be reviewed to include strategies for capacity building to generate and manage country specific reliable, quality and segregated data and indicators as highlighted in Goal 17 of the SDGs and in Article of 31 of UNCRPD among others. This could be done by promoting establishment of CBR/Disability Management Information Systems (DMIS) or mainstreaming CBR and disability data in respective country national bureau for statistics.

Recommendations for the Review of the CBR Guidelines

Considering the current trend, there is need for collaborative efforts to review the CBR Guidelines to:

- a) Limit rehabilitation to the health component so that its application is in line with applicable definition in the CBR Guidelines, namely, a process that involves implementation of a range of coordinated interventions at the level of policy legislation and programming across education, health, social and livelihoods sectors to promote equalization of opportunities, active participation and social inclusion for persons with disabilities.
- b) Redefine the empowerment component of the CBR Matrix from its current narrow focus on measures that promote self-representation and active participation of persons with disabilities, to 'Empowerment' as the ultimate outcome of CBR.

- c) Add a section on globally acceptable measures and/or tools (both qualitative and quantitative) for assessing the impact of CBR. This would among others, require inclusion of a provision in the CBR Guidelines to ensure that CBR is at all times aligned to national development indicators and targets and that, as a strategy, CBR can wholesomely be used for implementing UNCRPD.
- d) Equally reflect strategies for capacity building to generate and manage country specific reliable, quality and segregated disability data in line with Goal 17 of SDGs. This would require inclusion of a provision in the CBR Guidelines to ensure that CBR is at all times aligned to national development indicators and targets and that it can deliver on the CRPD.
- e) Establish possible linkages between elements of the various CBR components.

Conclusion

CBR Guidelines remain a viable tool for promoting active participation, empowerment and inclusion of persons with disabilities and their families in development agenda at both national and local/community levels. Despite country experiences since adoption of the Guidelines and the emerging issues in the field of disability and development such as adoption of SDGs, there is a need to review the CBR Guidelines and make them more effective in empowerment of persons with disabilities. CBR implementers should continue to be proactive and ensure that their programmes are in line with the national development programme, the post 2015 agenda and the UNCRPD principles. They should also continue to document and share good practices as well as remain in a state of vigilance regarding the development of post-2015 national policies.

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 - ** Zamo Soumana is the Disability Inclusion Advisor for CBM International for West and Central Africa Regional Office. He is the out-going chairperson of CBR Africa Network.

CHAPTER 2

Selecting Sustainable Development Goals and Targets for Greater Impact

*Alice Nganwa**

Summary

The Millennium Development Goals did not have much consideration for persons with disabilities. Great advocacy by the disability movement has led to the development of more inclusive sustainable development goals: “Leave no one behind”. Much as the goals are expected to influence policy development, they will only be realized with appropriate strategy development and targeting.

Introduction

The Sustainable Development Goals (SDG) 2016-2030 are intended to drive policy, resource allocation and development. This chapter discusses why disability as a development issue was left out of the Millennium Development Goals (MDGs) 2000-2015, and strategies to ensure its inclusion in the SDGs at national level. The context for the paper is Low and Middle Income Countries (LMIC) in sub-Saharan Africa.

MDG Bus and Why We Missed It

Long distance bus travel in Africa is rarely smooth. The road is bumpy and in the rainy seasons slippery. Sometimes the bus’ mechanical condition is ‘dangerous’. But the conversation is lively with laughter, sometimes breaking into singing and of course interrupted with advice to the driver.

In this chapter the MDGs and SDGs are compared to a bus ride in Africa.

The disability movement and the larger fraternity missed the MDG bus for several reasons. Identifying these reasons will inform development of appropriate

strategies to ensure that disability has a secure seat on the SDG bus.

Some of the reasons that made us miss the bus are:

Slow shift from the Medical to the Social/Rights-based Model: Progress from the medical model to the rehabilitation-focused Community Based Rehabilitation (CBR) and later to the multi-sectoral /multilevel CBR was a long process that spanned nearly twenty years. The UN statements on disability did not bind nations to commit to equalization of opportunity and participation. The 22 UN Standard rules and the UN Action Plan on Disability were not obligatory and their monitoring was not institutionalized in the member countries. The more binding UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN in 2008 when the MDGs were half way through their cycle.

Young Disability Movements and Fraternity: During the discussions that delivered MDGs, many Disabled People's Organizations (DPOs) in the south were either in formative stages or strengthening themselves. Service providers were also focusing on 'piloting CBR' while rehabilitation professionals were adjusting with difficulty to the social model of rehabilitation. There was therefore little conversation between the NGOs and Government bodies that were formulating the MDGs to make them inclusive.

Unarticulated Needs of Persons with Disabilities for the MDGs: The disability movement presented a statement to the UN specifying their needs within the MDGs in 2010, five years before the target date for attaining the goals. Although resolutions were made that included disability such as 'Keeping the Promise' (UN 2010), it was too late for meaningful application at national level. At the local level, DPOs such as the National Union of Disabled People of Uganda demanded for inclusion in poverty eradication programmes (MDG1) but little was specified for the other goals. Even within Goal 1, DPOs emphasized income over other issues such as malnutrition among children with disabilities.

Internal Rhetoric: Despite the bus leaving us, we could have found a way of getting on especially since the agenda of the MDGs meets the most urgent needs of Persons with Disabilities. The delay was largely due to 'campaigning within ourselves' at national, regional and global meetings.

CBR Africa Regional Conferences are often concluded with resolutions, many of which target Government officials who rarely attended disability conferences. Actualization of the resolutions and their respective follow up is often not strategic.

However, this does not mean conferences and meetings have not yielded results. They have helped shape and reshape understanding of disability and improve approaches to inclusion. The meetings have also provided platforms for persons with disabilities and service providers to discuss joint positions.

The Divide in Approach between DPOs and Service Providers: The disability movements in many nations were born out of a struggle against society including service providers who were using the charity and medical model. The extreme leaders of the movement preferred services ‘for and by persons with disabilities’ and this often resulted in conflict with service providers. Lately, the thinking has changed to partnership and this shift is demonstrated by emerging Community Based Rehabilitation activities led by persons with disabilities. Only a few DPOs in the North have yet to accept CBR as an approach that can deliver the CRPD. Although this is not a prominent reason for the delay in joining the MDGs, it contributed to the internal rhetoric.

Getting on and Participating in Steering The SDG Bus

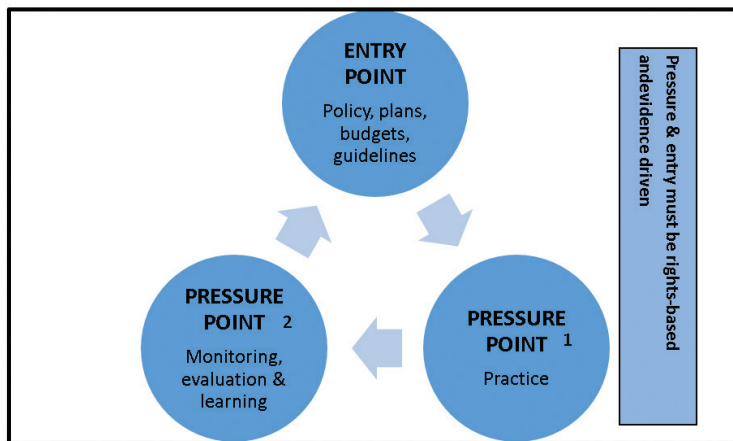
Disability is on the SDG bus. The timely, strategic and persistent campaign by WHO, International Disability Alliance (IDA) and International Disability and Development Consortium (IDDC) should be applauded. Of great importance is the context of ‘leaving no one behind’ in which the SDGs were developed and is reflected in a number of targets that provide for the most vulnerable. Among these, disability has five targets.

Now that we are on the bus how do we move forward to participate in steering it?

Focus on specific SDG Goals and Targets

Attempting to include disability in all 17 goals may work against us due to our low capacity. At the Fifth CBR Africa Conference in Nairobi 2015, Steven Chacha from ‘Beyond 2015’ suggested that the disability movement needs to identify the goals and targets that are of greatest leverage to persons with disabilities. He recommended focusing on national strategic and annual planning as entry points. In the UN report on ‘Disability and the Millennium Development Goals’ (2011), two tactical points are suggested: entry points and pressure points. The diagram below presents where the two could be applied in developing countries.

Figure 1: Tactical Points for Including Disability in SDGs



Entry points are strategic for negotiating and if necessary demanding for inclusion in documents that influence resource allocation and practice. Examples of ‘entry point’ documents are policies, guidelines and national strategic plans. Entry points are best used at national level so they can penetrate the whole country. However, in highly decentralized Governments, entry points can be at sub-national level. Pressure points 1 and 2 are important at implementation level to ensure service providers and managers abide by set national and international commitments.

Identify SDG Targets and Apply Pressure

In order to identify SDG targets that have significant leverage, the disability movement needs to use project evaluation reports to articulate needs of persons with disabilities and identify SDG goals and targets that best respond to the needs of the most vulnerable. A decision then needs to be made whether to use the selected targets at ‘entry point’ or ‘pressure point’.

If the application is at the pressure points, the capacity of DPOs and individual persons with disabilities should be built around the selected targets. This will sharpen advocacy, focus training and supervision and produce tangible results because of sustained application of pressure. If the pressure is to be effective it should be evidence-based which calls for research and development of papers based on programme monitoring, evaluation and learning.

All 17 goals are important; however, as mentioned earlier, best results will be attained by focusing resources on a few strategic goals. Based on personal experience, the author recommends that all targets that mention disability become campaign points. In addition, selected targets on poverty eradication, health, education, employment and Information Communication Technology (ICT) are strategic for persons with disabilities in low and middle income countries. SDG targets on donor funding are equally important. National and international DPOs should use donor-directed targets to apply pressure on development partners to use the twin-track approach proposed by DFID. One track mainstreams disability in development programmes and the second track provides a special platform that focuses on persons with disabilities to enable them 'catch-up' with the rest of society. The table below describes the relevance of the suggested goals.

Table 1: Critical Goals that are of Strategic Importance to Persons with Disabilities

Goal	Relevance
Poverty eradication	Persons with disabilities are among the poorest and are over-represented in this category.
Health	Rehabilitation sometimes requires medical procedures. Persons with disabilities are usually excluded from health care and yet health is critical for education, livelihoods, independence and inclusion.
Education	Persons with disabilities require education and training for knowledge and skills. It is the foundation for livelihood development to facilitate poverty reduction and empowerment.
Employment	Employment is a key determinant of well-being. Persons with disabilities rarely find employment and yet they need it for independent living.
ICT	Without ICT persons with disabilities especially the hearing and visually impaired have no access to information, quality education and communication. Accessible ICT is a right.
Donor funding	Donors influence national policy and resource allocation. Funding policies that promote the twin-track approach will ensure inclusion of disability in all the donor funded programmes.

Unified Voice from the Disability Fraternity

As mentioned earlier in the chapter, one reason the MDG bus was missed was the discordant and delayed voice from the disability fraternity. The disability movement, families and service providers need to unite in advocacy. In addition, the disability movement must be seen to be compassionate with other causes that affect vulnerable people. This way, more voices will join the cause for rights of persons with disabilities. CBR is strategically placed to bring about a united voice on disability and through its cross-sectoral, multi-level approach to embrace collaboration / support from other vulnerable groups.

Conclusion

The disability fraternity missed getting on the MDGs but is adequately provided for in the SDGs. In order to maximize the SDGs, DPOs must apply lessons learnt from missing the MDGs, be strategic and focus on the goals that have greatest leverage on the lives of persons with disabilities. Rights based advocacy that is evidence led should be applied at entry and pressure points at national, sub-national and community levels. Only then will persons with disabilities use the advantage gained from priority goals to enjoy the provision in remaining goals.

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CHAPTER 3

No Need to Reinvent the Wheel: Disability Mainstreaming for Poverty Reduction

Sarah Rule, Hubert Seifert**, Paul Kamau Mbugua****

Summary

CBM has worked in the field of livelihood development for over four decades, reaching over 100,000 people annually through a range of different approaches, including vocational training and skills development, formal and self-employment, promotion of cooperatives and micro finance. The overarching aim of these interventions has been to enhance the livelihood opportunities and increase the socio-economic empowerment of people with disabilities in marginalised communities by creating appropriate skill development, decent work and financing opportunities. This has enabled CBM to build a very successful track record in disability inclusive programming. The following article outlines strategies to ensure the full and equitable inclusion of persons with disabilities in formal and informal financial services through mainstreaming.

Introduction

As the United Nations and member countries deliberated what was to follow the Millennium Development Goals, it was determined that the greatest global challenge currently is to eradicate poverty (United Nations, 2015).

Literally hundreds of millions of persons with disabilities are capable of working and contributing to the economic well-being of their families but find themselves unbanked and excluded from the global and national economies.

At a macro-economic level, the World Bank estimates that between 5% and 7% of GDP is lost due to the economic exclusion of persons with disabilities. At the micro-economic level, financial service institutions are losing out on a large and

attractive market segment. Persons with disabilities comprise as much as 15% of an average population (World Report on Disability, 2011) yet based on anecdotal evidence, only 0.5% of current microfinance clients come from this under-served community. Disability inclusion represents a wonderful opportunity to “*do well by doing good*” – an achievable win-win situation for nations and their citizens and for inclusive financial service providers.

Persons with disabilities in low and middle-income countries are not only exposed to the same factors that cause poverty for others; they also face barriers that limit equitable access to health care, education, skills development, social participation and other services, further reducing their chances of securing decent work. These barriers include a lack of information about rights, benefits and opportunities for economic empowerment, inaccessible workplaces and public transport, as well as negative stereotypes and deep lying prejudices about persons with disabilities or their lack of abilities.

There are additional barriers in gaining access to micro finance institutions and financial services through banks and savings groups, such as a lack of physical access, and the absence of sign language interpreters and Braille signage. Negative attitudes and misunderstanding on the part of both financial institutions and persons with disabilities can however be greater obstacles. For example, it can be difficult for persons with disabilities to become members of savings or loan groups because group members do not consider them as credit-worthy.

It is imperative that we break down these attitudinal barriers, which often lead to poverty and marginalization – even within the person’s own family. When given the opportunity to take part in economic empowerment initiatives, persons with disabilities are as productive and efficient as non-disabled persons doing the same job. The social capital aspect through improved self-esteem, and the respect of and acceptance by others is also an important factor to consider.

The Legal and Business Case

The landmark UN Convention on the Rights of Persons with Disabilities specifically mandates economic inclusion programmes. Article 27 of the Convention underscores the important role that economic empowerment plays in integrating persons with disabilities into civil society. Indeed, ratifying countries are required to promote opportunities for formal employment, self-employment, entrepreneurship, the development of cooperatives, and starting one’s own business, as well as inclusive social protection.

In strategic economic-development terms, inclusive social protection involves enabling persons with disabilities to make the transition from being recipients of tax-funded social assistance to being contributors to social insurance systems.

While the legal and moral basis for inclusive livelihood development is solid, the business case is equally strong. According to the World Report on Disability (2011), by the age of sixty, 40% of humanity has some form of acquired disability, and the demographic reality of an aging global population is unquestionable. This creates an impetus for societies that are inclusive of person with disabilities. A financial institution that distinguishes itself by its high accessibility standards will have a competitive advantage in future over those that do not. Doing the right thing is also good business, and this needs to be emphasized to all financial institutions.

The International Labour Organisation (2011) states that people with disabilities make good, dependable employees and several Microfinance Institutions (MFIs) in India have come to the conclusion that they actually make better clients. For example, Annapurna, ESAF and Equitas, three MFI partners of the Centre for Financial Inclusion at Accion (CFI) in India, believe this strongly. They plan to obtain good data in the coming years to substantiate this conclusion. Many cases document comparable productivity, lower accident rates and higher job retention rates between employees with disabilities and a company's general workforce. Hiring people with disabilities can contribute to the overall diversity, creativity and morale in the work place and enhance a company's image among its staff, community and customers.

Numerous corporations including DuPont in the USA, Carrefour in Europe and Asia, and KFC restaurants operated by deaf persons in Cairo have discovered that employing persons with disabilities makes good business sense. An IT company in Bangalore, Vindhya Info media, in which Accion (a USA based action-oriented think tank working toward full global financial inclusion) has an equity investment has employed over 900 persons with disabilities, which represents 90% of their workforce. Design Mate in Ahmedabad employs 340 persons with disabilities as 3D software developers. When recruiting staff, they give priority to persons with disabilities as a successful business model, based on their observation that persons with disabilities are more dedicated and productive than employees without disabilities and have lower attrition rates when offered an accessible and conducive workplace.

Despite enormous physical, communication, attitudinal, legal and process barriers, millions of persons with disabilities are successful in business and have achieved financial independence. But most of their success has been based on individual efforts, family, or support from development organizations, and these are the exception rather than the rule.

What these trail blazers teach us is that small accessibility changes and modest support can transform life outcomes. By lowering the barriers to financial inclusion (often in very low-cost ways) many more can become economically self-sufficient, have the opportunity to earn a living through work they choose on an equal basis with others, and serve as inspirational role models. In a series of small-scale initiatives across multiple continents, this is exactly what has occurred. It is time for the lessons from such efforts to be fully leveraged and brought to scale.

Based on their extensive experience, CBM and the Center for Financial Inclusion at Accion (CFI) have developed inclusion guidelines, position papers and a reference guide to serve as disability-inclusive tools for implementation of livelihood and financial inclusion programmes. These tools can be used to create awareness and offer guidelines for economic empowerment programmes, financial institutions and savings and loan groups to make inclusion of persons with disabilities a reality.¹

People with disabilities have the same needs for a broad range of financial services as other community members, including a secure and convenient place for savings; access to credit for income smoothing and investments; easy money transfer; access to automatic teller machines; risk, life and health insurance; and social protection such as pensions. Financial institutions, employers and development organizations are encouraged to facilitate unhindered access to these services and to undertake the following:

A. Strengthen the Institutional Commitment and Code of Ethics

Concrete buy-in from senior leadership and all staffing levels to ensure a good level of understanding of the concept of inclusion and rights of persons with

1 http://www.cbm.org/article/downloads/78851/CBM_Inclusion_Made_Easy_-_Part_A.pdf
http://www.cbm.org/article/downloads/78851/CBM_Disability_Inclusion_-_Livelihood.pdf
http://www.cbm.org/article/downloads/54741/did_series1_The_Future_is_Inclusive.pdf
<http://www.centerforfinancialinclusion.org/programs-a-projects/pwd>

disabilities. Develop a code of ethics with specific guidance on how employers must treat clients and potential clients with disabilities, and provide staff training and monitoring mechanisms to ensure full compliance.

B. Review and Amend Key Policies to Prevent Discrimination

Review policies, guidelines and practices, examine client recruitment methods, loan application and interview processes, staff incentives, and the way information is collected, stored and presented. Ensure that all references to direct or indirect discrimination against persons with disabilities are amended or removed. Check for discriminatory practices amongst employers/employees that are unintentional, or due to traditional belief and practice, faith-based prejudice or lack of information.

C. Entry into Partnerships with Local Disability Organizations

Customization is essential to success. Ensure compliance of tools, training courses and guidelines with local legislation, policies and needs by subjecting them to review by Disabled Peoples Organizations (DPO) and other stakeholders. DPOs representing civil society and government-appointed national disability councils exist in almost all countries and offer advice or training on inclusion of persons with disabilities in mainstream settings.

D. Staff Training

Train staff to increase their awareness and acceptance of the national and international legal framework concerning the rights of persons with disabilities. This will emphasize the credit-worthiness of clients with disabilities, citing relevant examples. Offer sensitivity training at all organizational levels to increase the ability of staff to become proactive, and sensitize other key stakeholders on the importance of non-discrimination. Special attention will be paid to the training of loan and field officers, and others who will interact most with clients with disabilities.

E. Hiring of Persons with Disabilities

Actively recruit persons with disabilities at board and staff levels, and encourage persons with disabilities to apply for vacancies. Ensure that human resource policies take into account disability-specific needs such as physical accessibility

and access to information and communication technology. Interaction with staff and clients with disabilities ensures that inclusion becomes part of the permanent corporate culture.

F. Reasonable Accommodation and Universal Design

Clients with disabilities should not be excluded from using financial services due to the barriers already highlighted earlier.

The UN Convention on the Rights of Persons with Disabilities obliges employers to provide reasonable accommodation to their staff so that they can take up employment opportunities on an equal basis with others.

Such measures can include physical access ramps, accessible toilets, and the availability of information in Braille or through sign language interpreters. An accessibility audit can help to identify where change is needed.

G. Mainstreaming Committee

Inclusive livelihood requires commitment at all levels in planning, implementation, monitoring and reporting, to ensure consensus-based approaches, and to oversee that the needed changes are made effectively and efficiently. The establishment of a mainstreaming committee consisting of persons with disabilities and trained staff from key departments is recommended. This group should be responsible for developing a mainstreaming action plan, monitoring implementation, and reporting to senior management.

H. Risk Assessment Tools

Financial institutions should develop disability-specific risk assessment tools and offer insurance covers to ensure that persons with disabilities are not left destitute in case of failing health or due to advanced age. Since this group is at a high risk for any financial institution, developing a risk assessment tool could identify corresponding mitigating measures. For example, incorporating special insurance for these populations at risk will promote inclusion.²

2 Complete tools and training, as well as recommendations A-H, can be found at <http://www.centerforfinancialinclusion.org/programs-a-projects/pwd/framework-for-persons-with-disabilities>

In conclusion, disability is both a cause and a consequence of poverty, contributing to increased vulnerability and social exclusion of persons with disabilities from mainstream socio-economic activities. For the majority of persons with disabilities in the world, self-employment through micro enterprise development represents the most viable form of economic activity. The main barrier to a greater up-take of informal sector work by persons with disabilities is lack of access to comprehensive financial services including credit. Therefore, existing financial institutions and services must be opened up to persons with disabilities to make inclusion a reality.

The United Nations 2015-2030 Sustainable Development Goals make explicit reference to persons with disabilities and carries the tagline, “Leave No One Behind.” It is indisputable that, to meet poverty-reduction targets, persons with disabilities must move from the periphery to the centre of the world’s poverty alleviation effort.

Brief about Organizations mentioned in this Chapter

CBM and ACCION urge the global community of practitioners to dismantle the barriers that up to now have precluded the vast majority of persons with disabilities from access to finance, livelihood and economic participation, and facilitate equitable access to all mainstream financial services to achieve universal inclusion.

CBM is an international Christian disability development organization, committed to improving the quality of life of persons with disabilities in the poorest countries of the world. With over 100 years of professional experience, CBM works alongside 600 local, national and international partner agencies in the fields of healthcare, education, rehabilitation and livelihood development reaching about 40 million people annually 64 countries (2014).

The Center for Financial Inclusion at Accion (CFI) is an action-oriented think tank working toward full global financial inclusion. Constructing a financial inclusion sector that reaches every one with quality services will require the combined efforts of many actors. CFI contributes to full inclusion by collaborating with sector participants to tackle challenges beyond the scope of any one actor.

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CHAPTER 4

The PIE Model and Tools: Meeting the Need for a Systematic and Participatory Approach to Evaluating the Impact of CBR

Mary Wickenden, Huib Cornielje**, Priscilla Nkwenge****

Summary

This paper describes the research project to develop PIE, a new approach to participatory impact evaluation for CBR. The primary aim of this project was to develop a conceptual model and an approach to impact evaluation and a set of tools to measure the impact of CBR on people with disabilities and their families and communities. The resulting new model for impact evaluation (PIE - Participatory Inclusion Evaluation) was developed during an Australian government (DFAT) funded research project (ADRA) during 2013-2016. The final result is a set of participatory tools with an accompanying handbook, providing a structure for an evaluation process. The handbook includes instructions for initial participatory situational analysis, topic guides for interviews with CBR managers and with people with disabilities and their relatives, guidelines for focus group discussions with strategic partners and groups of people with disabilities (e.g. Disabled People's Organizations and self-help groups), and suggested formats for a community validation meeting and for analyzing data and reporting.

Introduction

Current Ideas about CBR

The World Health Organization first introduced the concept of Community Based Rehabilitation (CBR) in the late nineteen seventies. CBR was designed to enhance quality of life for people with disabilities in low-income countries through

community initiatives. It is a concept, which has evolved through trial and error over the last 30 years, alongside perspectives on disability also changing, and it also varies greatly in the way it is operationalised across countries and cultures. Over the last fifteen years, achieving human rights, equality and inclusiveness for people with disabilities have increasingly become the focus of CBR. So CBR has gradually moved from having a predominately individual impairment focus, into a rights-based strategy aimed at equal opportunities and inclusion of all. Thus CBR is now expressly concerned not just with individuals with disabilities, but with their families and the community as a whole. The WHO CBR Guidelines launched in 2010 are clearly influenced by and linked to the UNCRPD (UN, 2006) and the realisation of peoples' rights as citizens.

The principles of CBR continue to evolve as reflected in the current discussion about moving towards the term 'Community Based Inclusive Development' (CBID). It does not just set out to address impairment aspects of people's disability but also aims to tackle the poverty, reduced opportunities and social exclusion that people with disabilities often experience (WHO, 2011). The Sustainable Development Goals (2015) now mandate national states to think more inclusively and CBR can play an important part in this aspiration, although it is not mentioned explicitly. It is an approach whereby increasingly people with disabilities and caregivers define their own needs and negotiate with service providers and other community stakeholders across sectors, as well as with policymakers, to improve their living circumstances and to play their full part in society alongside their nondisabled peers.

The Need for a Systematic Approach to Evaluation of CBR

Despite this evolution of CBR, evidence about its impact has remained sparse throughout its history, especially at impact level (Weber et al, 2015). Evidence is mostly anecdotal and does not address important issues such as links between outcomes, impact and cost-effectiveness, nor importantly, the issue of the extent to which change can be attributed directly to CBR or whether it is a rather a contribution to change that we looking for (IDRC 2004, White 2009, Bamberger et al 2010, Australian Aid, 2012). This may be because CBR is often poorly defined, broad in scope, and many differences in the structure and organisation of programmes can be seen between and within countries. There is an urgent need to develop ways to evaluate the outcome and impact of CBR programmes at individual, household and community levels. We need to be sure to ask the right

people the right questions in the right ways (Garcia & Zazueta, 2015). This will help planners and practitioners to: improve CBR services, increase efficiency, move from a patient or client-focus alone to a community movement and be responsive to people with disabilities and their families' concerns at the household level. Additionally, more widely where inclusive and enabling environments are not being given attention it will raise awareness of these needs, and provide evidence of the effectiveness of CBR as a strategy (Baum et al 2006, Befani et al 2014). Once we know what works best at the various levels of intervention, we can do more of these.

CBR Evaluation – a Brief Overview

There have been a number of notable efforts to review, clarify and develop systems for monitoring and evaluation of CBR. Early on, Wirz and Thomas (2002) tried to bring order to the unlimited diversity of indicators being used. They presented a helpful summary of the literature on the use of indicators in CBR in the 1990s, and proposed three domains for classifying indicators:

- 1) Maximising the potential of the person with disability,
- 2) Service delivery,
- 3) The environment in which the person with disability lives.

Their paper brings together indicators that were used in CBR programmes at the time or were derived from the types of activities being implemented in CBR programmes. This was a time prior to the UNCRPD (UN, 2006), when the current more 'inclusive development' focused conceptualisation of CBR was just emerging. A contemporary version of their proposal would likely include a stronger focus on realisation of human rights and more explicit mention of mainstreaming and inclusion.

Velema and Cornielje (2003) helpfully proposed five domains in which data might be collected in CBR programmes:

- 1) Outcomes pursued for the person with disability,
- 2) Provider-client relationship,
- 3) Commitment to involve others,
- 4) Services offered (type, coverage, quality),
- 5) The interaction between the CBR programme and the environment in which it operates.

In 2008, the same authors and then others repeated their call for more effective monitoring and evaluation, so as to create the evidence base that CBR needs to develop further (Finkenflugel et al 2005, Mannan & Turnbull 2007, Kuipers and Harknett 2008, Kuipers et al 2008, Adeoye et al 2011).

Bowers et al (2015) explored the long-term attributable impact of CBR in North West Bangladesh. However, their study scope was limited to self-help groups – a component of, rather than a full CBR intervention, which is a much more complex, multidimensional and multi-sectoral. CBR is very context-specific and its success or failure depends on a wide range of factors.

Other authors have also contributed to the theoretical discussion but none have proposed a specific structure or set of tools for evaluation per se (Finkenflügel et al 2008, Lukersmith et al 2013, Udoh et al 2013, Grandisson et al 2014). Madden and colleagues (2015) have usefully designed a flexible structure for ongoing monitoring (as opposed to intermittent evaluation) of CBR work and this is a definite step forward in providing CBR managers with a basis on which to design their own monitoring systems. Lemmi et al (2016) have recently systematically reviewed a selective group of CBR programmes' effectiveness for particular impairment groups and confirmed that they were broadly beneficial, however they, like others, identify a CBR 'evaluation gap.'

During the first World Congress on CBR in Agra (WHO, 2012), the WHO convened a workshop to launch a process of indicator development for CBR, structured around the CBR Guidelines (WHO 2010) and CBR Matrix (WHO, 2004). Eventually the process resulted in an evaluation manual developed in partnership with IDDC (WHO 2015). This presents a 'ready-to-roll' set of questions using a smart phone App based methodology for a quantitative survey. This captures the situation of persons with disabilities in communities, compared to non-disabled people. This is structured in relation to the 5 components defined by the CBR Matrix: health, education, livelihood, social life and empowerment, with roughly one question per element, plus a few extras. Over time the data derived from this survey could play an important role in evaluating whether peoples' lives have improved across the 5 components and in comparison with the rest of their communities.

However, this tool does not explicitly measure what role CBR has played in any improvement seen, although it might show change in people's situation over time if the survey is repeated at time intervals. So the question about actual

attribution of change or more realistically, the contribution of a CBR programme to the measured changes in a person's status remains unsolved. We still need to know what CBR does, whether and what sort of impact it has and what different stakeholders think of its usefulness and importance. Most importantly what do people with disabilities (and their families) think CBR does to improve their lives and how? This demands a more qualitative and participatory approach to complement quantitative measures (Hartley & Muhit 2003, Catley et al 2007, Chambers et al 2009). It also requires data at the household and community level as well as asking about individuals' situations.

Challenges in CBR Evaluation

One of the most important questions, maybe the most important in CBR evaluations, is a question that seldom can or will be answered:

"How many people with disabilities moved into your programme at the beginning of the year – and how many moved out of your CBR programme at the end of the year?"

Ideally we want to know how many beneficiaries were successfully 'rehabilitated' or, differently phrased, how many people are now participating more in society, living an independent life, are empowered or feel that they are included successfully in society. While most managers cannot answer these deceptively simple questions, the more intriguing qualitative questions about the how and the why of this success (or lack of success) are even more beyond reach. The reasons for this are multiple:

- 1) CBR is not a simple intervention but a complex multi-sectoral and multidisciplinary approach, therefore untangling how changes happen and who is influencing what becomes difficult. There is often no easily assessed linear route, which led to change. Many factors may have been important in the road to change.
- 2) CBR is not just an intervention or series of interventions directed at people with disabilities themselves, but is also directed at the level of families, service providers and society at large. Evaluations need to explore these different levels, which will also interact and influence each other.
- 3) Monitoring, which should inform evaluations, is usually weak. Documentation of the activities of CBR programmes is often of poor quality, not focused and does not provide sufficient information to feed into good evaluations. Often client-records are limited or incomplete and

existing management information systems have little to offer evaluators (and managers).

The PIE Development Project - What We Did and Why

The research project to develop PIE, a new approach to participatory impact evaluation for CBR, arose out of the dissatisfaction of the authors and others with current CBR evaluation resources and practices. There is almost a complete absence of robust evidence that CBR can be a successful, appropriate and effective rehabilitation strategy and development approach in meeting the needs of people with disabilities, despite plenty of anecdotes showing that it can work. Our initial wish list was to develop an evaluation process that would:

- Be flexible – be useable in a wide variety of cultural contexts and types of CBR programmes
- Be participatory and inclusive - involving a wide range of stakeholders including men and women, boys and girls with a range of impairments and ages, service providers and other community stakeholders in the process
- Aim for an in-depth comprehensive process that would be carried out once every 3-5 years
- Make use of ongoing monitoring data collected and existing documentary evidence as well as collecting new information
- Use the principles of the UNCRPD, the WHO CBR guidelines and the CBR matrix as part of the framework for planning, collecting data, analysis and reporting
- Provide a structure to systemise planning, data collection, analysis and reporting of the evaluation
- Focus predominantly on impact, but also evaluate other aspects such as relevance effectiveness (including quality and access), efficiency and sustainability
- Unpack how change happens – by looking at relationships and who influences what and how
- Draw on existing approaches to evaluation from the broader international development and community development arenas
- Organise the evaluation to encourage active learning and future planning of the programmes as well as upward accountability

- Structure data and analysis in a way that would enable and encourage comparison across time or between contexts and programmes
- Provide clear and detailed instructions about how to carry out the evaluation, including guidance about flexibility, ethical issues, inclusive methodologies, analysis, validating findings and report writing

The primary aim of this project was to develop a conceptual model and an approach to impact evaluation and a set of tools which would be participatory and would measure the impact of CBR on people with disabilities and their families and communities. The resulting new model for impact evaluation (PIE-Participatory Inclusion Evaluation) was developed during an Australian government (DFAT) funded research project (ADRA) during 2013-2016.

Our thinking for this innovative approach to evaluation was influenced by theory and experiences from international development, mainly outside the disability arena. We reviewed and considered a number of contemporary models and methodologies used in other sectors including among others: Outcome Mapping and Harvesting (Earl et al 2001), Most Significant Change Stories (Davies & Dart 2005), the 5 Capabilities Approach (Keijseret al 2011), the WHO model for Chronic Conditions (WHO 2002), ecological models of human development (Bronfenbrenner 1977), PADEV (Dietz et al 2013) and Sense making (Kurtz & Snowden 2003). We found that all of these were relevant to participatory impact evaluation of CBR. They formed a starting point and various aspects were incorporated into the thinking behind the PIE approach and were gradually refined and adapted to meet our purposes. Besides these, use was made of well-known participatory methods such as drawing timelines, community mapping, focus groups discussions, individual interviews, collecting stories, use of visual means such as emoticon rating scales and photos to facilitate discussion (Bergold & Thomas 2012).

During the 3 year project, we gradually refined our draft approach and tools, and trialed these in 4 CBR programmes, 2 each in Uganda (Kayunga, Kasese) and Malawi (Machinga, Mzimba). These trials were invaluable in telling us what worked well and what needed further adaptation. The trial evaluations were carried out by in-country teams of 3 people, who between them had experience of disability, evaluation and community development and were gender balanced. They were supported by in-country advisory groups who had further specialist knowledge of CBR and the context. These colleagues all contributed greatly to

the design and refinement of PIE at each stage. We were also advised by an international group of experts.

The final result is a set of participatory tools with an accompanying handbook, providing a structure for an evaluation process. The handbook includes instructions for initial participatory situational analysis, topic guides for interviews with CBR managers and with people with disabilities and their relatives, guidelines for focus group discussions with strategic partners and groups of people with disabilities (e.g. Disabled Peoples Organizations and self-help groups), and suggested formats for a community validation meeting and for analyzing data and reporting. These materials are available for download. The web addresses are given at the end of this chapter. More theoretical conceptual discussions about our choice of approaches and methods will be published soon.

The PIE Approach – a Short Overview

The PIE approach and toolkit is a rigorous but flexible structure to guide CBR evaluation processes, in diverse contexts. A unique aspect is the conceptualization of CBR programmes as comprising a nested system of 3 distinct types of stakeholders who relate to each other:-

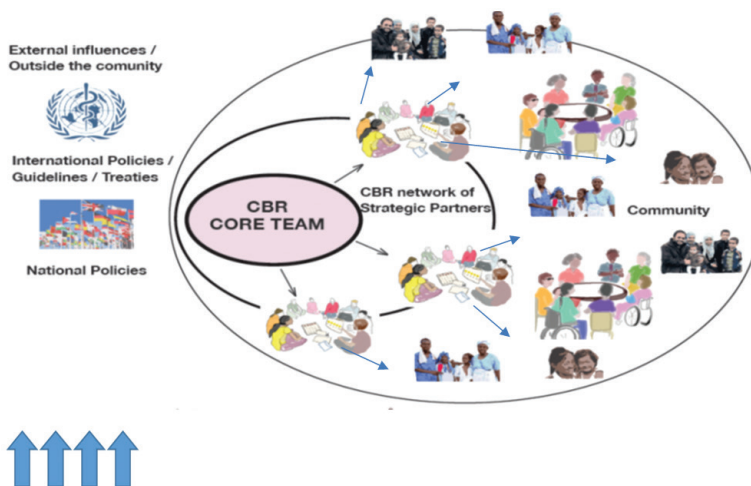
- The ‘CBR core team’
- A network of ‘Strategic Partners
- People with disabilities and their families and DPOs

As illustrated by figure 1 below, the PIE approach borrows from ‘Outcome Mapping (OM)’ (Earl et al 2001) methodology. It emphasizes that all these stakeholders have potential contributions to make, focusing on the degree of influence they each have in bringing about change. In order to find out what changes are happening, each of these groups need to be consulted during the evaluation, as their perspectives will be different, may be contrasting or complementary, both being important. Using an OM inspired approach, the intervention, (whether CBR or a forestry or sanitation project or whatever), can be conceptualised as having its impact by working through relationships between different actors who are seeking to bring about change. It focuses on people and how their behaviour has changed. This way of thinking about CBR should be applicable whatever type of programme is being evaluated.

The 'CBR Core Team' (usually a manager and some other paid and or volunteer team members) work with a number of other organisations and groups – the Network of Strategic Partners (who may be government and or non-government service providers, advocacy/lobby groups, agencies, business, faith and other community organisations). The Core Team and the Strategic partners may collaborate on service provision, training, awareness raising, lobbying and financing. They will work directly and or directly with the people with disabilities and their families at the household level.

For example: the Core Team might provide training and support to the local health service to help them to be more inclusive. A local business might be keen to employ some people with disabilities and ask for advice about how to do this. The Core Team might liaise with local police and judiciary about access to justice for people with disabilities. In such cases the Core Team have made a difference by working through the Strategic Partners, not directly with the people with disabilities. The latter may experience some impact, but they may not be aware of all the stages in how this has come about.

Fig 1 A Model of how CBR Works Inspired by Outcome Mapping



The PIE focus, which is mainly on outcomes and impact, is unique as it incorporates the principles of the UN Convention on the Rights of People with Disabilities (UN 2007) as they are outlined in the WHO CBR Guidelines (WHO, 2010). Impact looks for improvement in 3 aspects:

- ✓ **Inclusion:** having equal access & opportunities, feeling of belonging/ engagement/ connection in the community
- ✓ **Empowerment:** having control and choice in life, confidence and self-esteem to realise one's own goals and claim rights
- ✓ **Living Conditions:** having the basic needs of life, both physically & emotionally, better health, economic security, more stability, feeling more at ease and able to manage well

PIE Evaluation Framework

The whole PIE approach to collecting evidence about what the CBR programme is doing is summarised in an Evaluation Framework which guides the evaluators thinking. It lays out who needs to be consulted, which tools used and aspects explored with each type of respondent. The exact evaluation plan will depend on the type of programme and what its' focus is.

7 Stages in the PIE process

PIE has seven stages, each with its own specific tools or methods. The handbook and the set of tools provide detailed guidance about each stage. There is some flexibility in the process, so evaluators can choose which and how much data to collect according to the context and depth of evaluation required. Choices may depend on the requirements of a funder and on time and resources available.

Fig 2. PIE has seven stages



Reflections From the Field – the Experience of one of the Evaluation Team in Uganda

Priscilla Nkwenge was involved in both of the PIE field trials in Uganda. She had previous experience in evaluation and in community development but not in disability work or CBR.

“My experience in participating in the PIE development is that it focuses mainly on the kinds of changes that people experience in their lives and to what extent the CBR programme has contributed to these.

Past evaluations that I have experienced have tended to focus on the processes and outcomes of the projects/ programmes with less attention on actual impact. However this may be attributed to the kind of methodology, tools used and the longer time frame required to conduct an impact evaluation. Evaluations looking at outcomes have tended not to lead to change in action plans. This new evaluation took longer than others I have done and used different kinds of tools and methods.

The PIE is participatory in nature, as the main stakeholders were very involved, including the closely involved service providers (Strategic Partners). This enabled the research team to collect a lot information on what was happening in the different CBR Components.

Prior to arriving in the field the research/evaluation team collaborated with the CBR managers who played a vital role in mobilizing the CBR core team to arrange various evaluation events. These were key in gaining participation of important and knowledgeable people in the various key tools in stage one of the evaluation such as the Big Mapping, Timeline and Stakeholder Mapping. These three tools are benchmarks for planning and helped in identifying categories of participants to interact with during the main data collection stages.

Carrying out the PIE in the real situation, revealed how the new tools worked and what needed refining, for instance the 5 Capabilities was useful in facilitating the Core Team self-assessment. This tool created awareness in the group of their strengths as well as weakness within their systems and led to them taking up actions later. For example the Core team in Kasese district realised that the health department was not involved enough in the CBR programme and efforts were made after the evaluation to bring them on track. Furthermore the gaps that were identified during the process of stakeholder mapping were identified for action. This tool gave me as an evaluator a deeper understanding of the structure of the programme.

The entire process of the PIE evaluation had the effect of increasing ownership of the programme by both the implementers (Core team and Strategic Partners) and the end beneficiaries. This was particularly achieved through the final validation meetings, held with all the participants and other community members. This is a 'must do' process for any evaluation, since it enables the evaluators to review and quality assure the information gathered and checks out what it all means with the community. It definitely enhances learning and action planning. It also increases accountability as plans made at the meeting are then transparent and public, and could be open to later review.

The most difficult aspect of the evaluation process for me as an evaluator was the data analysis stage especially in the first trial in Kayunga. A lot of information was collected from individual interviews, focus group discussions, as well as 'most significant change' stories. However, much was left out during our report writing stage simply because the team didn't have clear guidance about how to analyse and summarise so much information. However before the second trial in Kasese an evaluation framework was developed which made it much easier to carry out data analysis more efficiently, since the framework was more specific on the key result areas. It is therefore important to have a clear analysis framework developed at an early stage to save time and resources.

Inadequate access to monitoring documents/reports was a difficulty we encountered. There were insufficient documents provided by the CBR managers to provide background information. This was largely attributed to poor storage of reports as well as limited record-keeping on the numbers, type of disabilities served etc.

Sign Language was another challenge for the evaluation team. Individual Interviews and focus group discussions were conducted with deaf people, however there was a difficulty with identifying sign language interpreters who knew the appropriate sign language. This hampered the process.

As a new person in the disability arena there has been a lot to learn and appreciate about the lives of people with disabilities. I must say it was a humbling and great experience to be part of the PIE development. Listening to people's stories and seeing them so energetically advocating for their rights was inspiring. It is a very big step towards promoting inclusion more holistically in the African context today. With a previous background in M&E, the PIE study has equipped me with a broader outlook and more practical skills in conducting impact evaluations generally, as well as in the disability field. Having to be systematic and follow a process has polished my skills in tracking progress in other assignments that I work on."

Reflections on the Process and Challenges Encountered

Detailed discussion on the PIE development and the findings from the 4 trial evaluations will be reported in subsequent journal articles. However it is useful to reflect briefly here on what we learnt in the process of developing the PIE model, approach and tools. This was an iterative process which involved a great deal of consultation and discussion with our in-country teams and advisory group members. After each trial more adaptations and refinements were made.

Challenges Encountered During the Process

- Lack of monitoring data or documentation for review (e.g. statistics, annual reports etc.)
- Sampling difficulties with achieving really inclusive consultation (some impairment groups were difficult to reach for consultation – e.g. people with severe intellectual and complex impairments and their carers, people with psychosocial difficulties, those living remotely)
- Risk of selection bias from CBR Core team – choosing the ‘usual suspects’ and success stories
- Courtesy bias from participants - e.g. not feeling able to criticize / saying only positive things
- Large amount of very rich qualitative data – but difficult for evaluators to analyse and summarise
- Time constraints – a time consuming process which was demanding for the team

Responses from Participants to the Process

- Some people with disabilities did not know what CBR was expected to do for them or could potentially do, so their judgment was quite narrow
- CBR Core Teams found the initial mapping exercises and the 5 C’s self-rating of their own capacities as a team gave them new and useful insights into their work
- Networks of Strategic Partners had not previously seen themselves as part of CBR – not very aware of inclusive practice principles
- Group consultation activities and visually based tools such as using emoticon rating scales and photos were most popular with participants

- People with disabilities appreciated the opportunity to tell stories, discuss, rate services, make recommendations and contribute to future planning
- The Community Validation meetings where all participants came together to discuss findings, recommendations and future planning were very popular, broke down hierarchies, opened up opportunities for new links and collaborations across sectors

Unresolved Dilemmas in Relation to Evaluation of CBR

- o Attribution vs contribution focus - is it possible to show exactly who/what is responsible for change when CBR is a complex multi-sectoral system with many indirect mechanisms at play?
- o Difficulty with getting beyond resource constraints when things are not going well ('we can't do it any better because we have no money')
- o The challenges of balancing impairment focused and broader human rights/inclusive development agendas – the latter are more difficult to evaluate
- o The relationship between monitoring and evaluation – how can they combine and work together?
- o How can we best combine quantitative and qualitative methods and data?
- o Resourcing of evaluations – need for investment by funders in the time/cost of good evaluations – i.e. need to increase percentage of budgets allocated to monitoring, evaluation and learning (ME & L)
- o Use of external or internal evaluators? Pros and cons of different types of evaluators and the skills needed (especially re analysis)
- o How participatory can evaluation really be? (danger of tokenistic participation)
- o What happens to evaluation findings? Who reads them?
- o Relationship with planning? Do evaluation findings feed into change and how?

Conclusions

In conclusion we feel that the PIE approach will be able to contribute significantly to the practice of evaluation of CBR/CBID in its diverse forms. The structured approach helped make evaluation systematic, comprehensive and in-depth. It provides both a structure to follow, but also flexibility so that evaluation teams can adapt the approach to the needs of their particular assignment. It can be used

for both multi-sectoral programmes working across all of the 5 components of CBR or for more specifically focused programmes perhaps working only in one sector or with one age or impairment group.

One aspect that is both an advantage and a disadvantage is that it is a very in-depth process. This gives rich data and reveals much at the community level about what is going on, however this is demanding in terms of time and human resources. Evaluation is often underfunded so that only quick and superficial evaluations are done and we would argue that funders should increase the percentage of budgets spent on monitoring and evaluation to allow for in-depth evaluations such as PIE. Indeed we would also echo the need for better monitoring as well as more systematic evaluations and for the use of a combination of approaches both quantitative and qualitative in order to gain a holistic picture of what CBR/CBID programmes are achieving. The PIE approach is however still in development and we envisage a number of refinements and adaptations may be made once people start to use it. We hope however that it will contribute to demonstrating the impact of CBR/CBID on people with disabilities' lives.

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All those who participated in the evaluation, either as facilitators or informants including many people with disabilities and their families.

The PIE handbook and tools can be accessed online at the following websites

<http://www.ucl.ac.uk/research/a-z/participatory=development-impact>

[http://www.enablement.nl/index/php/165/Tools and materials.html](http://www.enablement.nl/index/php/165/Tools%20and%20materials.html)

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CHAPTER 5

Disaster Risk Reduction: Inclusion and Not Charity

*Maholo Carolyne Sserunkuma**

Summary

Many communities of Africa are greatly affected by disasters. Disaster risk is determined by level of vulnerability, which relates to capacity. Persons with disability are known to be highly vulnerable due to impairment, barriers, and limited access to capacity development or empowerment opportunities. Attainment of the Sustainable Development Goals requires inclusive disaster risk reduction strategies. There is urgent need to empower and enable persons with disabilities to mitigate their vulnerability and enhance their capacity in the fight against disaster.

Introduction

Community-based Rehabilitation (CBR) has been implemented for thirty years. It is known to be an appropriate strategy for empowerment and elimination of barriers to participation of persons with disabilities.

Disaster risk is a contemporary social challenge. Persons with disabilities are known to be highly vulnerable, yet often excluded from community disaster risk response and disaster reduction undertakings.

Could this be due a knowledge gap or the negative attitude towards persons with disabilities?

The UN Convention on the Rights of Persons with Disabilities (CRPD), Articles 11 and 32, require that persons with disabilities benefit from and participate in disaster relief, emergency response and Disaster Risk Reduction strategies.

Sustainable development has been redefined to become more inclusive, hence the recently declared Sustainable Development Goals' slogan of 'leave no one behind'.

In this chapter, we present the concept of disaster risk and how community based

rehabilitation is instrumental in developing inclusive disaster risk reduction strategies.

Community Based Rehabilitation

Community Based Rehabilitation, (CBR) is a strategy for rehabilitation, equalization of opportunities, poverty reduction and social integration of persons with disabilities (ILO, UNESCO, WHO 2004). It is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities.

The Convention on the Rights of Persons with Disabilities, describes persons with disabilities to include those who have 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 (Article 1). *'This is based on observation that the concept of disability is evolving and that disability results from the interaction between persons with impairments and the barriers that hinder their full and effective participation in society on an equal basis with others'* (UN,2006).

According to the World Report on Disability (2011), 15% of the population worldwide lives with a disability, of which 80% are in developing countries. Many persons with disabilities experience challenges such as poor health, limited access to quality education, limited economic opportunities and higher rates of poverty due to the barriers they face and lack of rehabilitation services. Disability is therefore a human rights and development issue.

Comprehensive rehabilitation services focusing on health, employment, education and social services are needed to enable children and adults with disabilities attain and maintain maximum independence, full physical, mental, social, vocational ability, and full inclusion and participation in all aspects of life (UN 2008).

The Rhetoric of Disaster Risk among Persons with Disabilities

Disaster risk is the likelihood of occurrence of any serious disruption in the functioning of a society that causes massive suffering, loss of lives or property and destruction of the environment to the extent that the affected persons cannot manage using their own resources.

THE DISASTER RISK EQUATION

$$\text{Risk [R]} = \frac{\text{Hazard [H]} \times \text{Vulnerability [V]}}{\text{Capacity to cope [C]}}$$

The risk of a disaster increases as the frequency or severity of hazards increases, people's vulnerability increases and people's capacity to cope (ability to cope with the consequences) is decreased.

Disaster risk arises from existence of things that are likely to cause harm (hazards) many of which exist in all communities where persons with disabilities live in combination with vulnerability. This is a typical situation of disaster risk.



Photo courtesy Maholo Carolynne

In Baale village Kagamba sub county Rakai district in Central Uganda, Lake Kijani Barola is key water source. However, people have constructed houses close to the lake. The area has also suffered great sedimentation. The house in the photo is a home for Sulaina, a child with cerebral Palsy. She is at a

high risk of experiencing the disaster. Sulaina is often locked up as parents fend for the family on the lake (Maholo 2012).

Vulnerability implies limited capacity. Impairment increases vulnerability of persons with disabilities and is worsened with lack of rehabilitation, assistive devices and the various barriers that restrict their participation. Vulnerability is assessed in reference to age, sex, disability, location and time in relation to the hazard.

Below is a typical disaster situation in Butaleja district, Eastern Uganda. Butaleja is known for rice growing in the swamps, hence causing a likelihood of disaster.



Located at the base of the Elgon hills, Butaleja is highly vulnerable to floods during heavy rains. Occasional mudslides from the mountains worsen the situation.

A farmer, struggling to rescue remnants of his harvest from a rice garden in one of the villages in Butaleja. (Photo courtesy Daniel Edyegu)



Residents cross a flooded stream in Doho Village in Butaleja District during the rainy season. (Photo courtesy Yahudu Kitunzi)

Can you then imagine life with challenges in seeing, hearing, movement, perception sometimes appearing separately and occasionally in combination?

These are some of the challenges shared by the persons with disabilities in Butaleja, Kalembe and Maholo (2013). Natural and man-made disasters tend to have a disproportionate impact on people with disabilities. In times of disaster, people with movement challenges experience hardships in escaping danger. Persons with hearing impairment may miss communication about what is happening and they stand a risk of being left behind as other people flee from danger. Without appropriate communication, persons with visual impairment miss important information which could save their lives. In this era of HIV and other deadly diseases, they hardly tell the test results nor can they access the necessary information. They rely on other parties who can easily manipulate situations to their own benefit.

Vulnerability among persons with disabilities occurs anywhere in the community. The children who are excluded from school are prone to home injuries such as

burns and violence. Some are abused in the home to the extent that they get babies whom they can hardly care for. School-going children are vulnerable to road traffic accidents while youths in the stage of exploration are highly vulnerable to all forms of sexual abuse, hence live in a state of high vulnerability to sexually transmitted diseases. Studies have presented the double tragedy experienced by women with disabilities sometimes abandoned with children whose fathers they cannot identify while a few men are occasionally abandoned with children.

In the deprivation trap by Robert Chambers (1997), disability/physical weakness, vulnerability, powerlessness and poverty form a vicious cycle. With poverty, children with disabilities are deprived of normal social, physical and cognitive development. The lack of rehabilitation, assistive devices and the necessary environmental modifications lead to exclusion in education, health, and employment intensifying poverty (WHO 2011), and worsening vulnerability. Exclusion and marginalization reduces the opportunities for persons with disabilities to productively contribute to the household and community development, which increase the risk of falling into poverty (Elwan, 1999). CBR is effective in addressing multiple deprivations, especially those experienced by persons with disabilities who live in rural communities.

Community Based Rehabilitation for Resilience Building

“Rehabilitation is a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life” (UN, 1982). “Rehabilitation provides disabled people with the tools they need to attain independence and self-determination” (WHO, 2013).

It includes all procedures that endeavor to lessen the disabling circumstances’ impact, to achieve social integration and hence participation in the mainstream of community life (WHO, 1981).

In all rehabilitation efforts, emphasis should be placed on strengthening the individual’s abilities and protection of rights, integrity and dignity. Undertaken within the family and community, CBR is cost effective, acceptable and sustainable. It also facilitates information sharing, learning and elimination of barriers to widen opportunities for persons with disabilities.

Resilience building is a disaster risk reduction concept. It entails enhancing the

capacity of vulnerable persons to identify, prevent, minimize, manage, cope and recover from dangerous situations. According to UNISDR Terminology and Disaster Risk Reduction (2009) resilience is the ability of a system, community or society exposed to hazards to resist, absorb, accommodate to and recover from the effects of a hazard in a timely and efficient manner, including through the preservation and restoration of its essential basic structures and functions.

Today, sustainable development is considered to be growth which is both inclusive and environmentally sound to reduce poverty and build shared prosperity for today's population and to continue meeting the needs of future generations (World Bank, 2013). This new thinking greatly influenced the development of Sustainable Development Goals (SDGs).

Attainment of the Sustainable Development Goals requires participation of all people in productive activities. Persons with disabilities are an important resource who can greatly contribute to economic growth and sustainable development. CBR facilitates community based inclusive development where persons with disabilities and their family members are part of all development initiatives with equal rights and opportunities. It involves appropriate assessment of persons with disabilities, enhancing their capacity and providing a favourable environment for participation in individual, family and community activities.

CBR is therefore an appropriate strategy for resilience building since it is aimed at *"empowerment and enablement of persons with disabilities to fully expand their potential with suitable aids and equipment, education, training and support from the community"* (Elwan, 1999). It increases accessibility to rehabilitation services for persons with disabilities living in rural and remote areas.

CBR mitigates vulnerability to disaster by enhancing capacity of individuals, families and communities to identify, their needs/challenges, and existing resources/facilities to develop appropriate interventions for their own transformation. CBR increases participation of persons with disabilities making them contributors and not mere beneficiaries hence giving them the feeling of attainment which motivates them into continuous contribution to community development.

With emphasis on having all activities implemented in the community, CBR encourages use of locally available resources which are cost effective, easy to replace, acceptable hence sustainable. Enhancing resilience of persons with

disabilities requires incorporation of CBR in all community development ventures for sustainability and to promote sustainable development. Participatory approaches, effective documentation, dissemination of evidence based good practice and continuous information sharing are instrumental.

Inclusion, not Charity, in Disaster Risk reduction

The UN Office for Disaster Risk Reduction (UNISDR) conceptualizes Disaster Risk Reduction as *“the concept and practice of reducing disaster risks through systematic efforts to analyse and manage the causal factors of disasters, including through reduced exposure to hazards, lessened vulnerability of people and property, wise management of land and the environment, and improved preparedness for adverse events. Resilience is the ability of a system, community or society exposed to hazards to resist, absorb, accommodate to and recover from the effects of a hazard in a timely and efficient manner, including through the preservation and restoration of its essential basic structures and functions”* (UNISDR 2009).

Disasters often hit the poor hardest. Persons with disabilities are among the most marginalized poor people in many communities; a state which worsens their vulnerability, limiting their engagement in economic growth and locking them up into a cycle of perpetual vulnerability. In many cases, persons with disabilities are unable to detect, prevent, manage, cope and recover from things that are likely to cause harm. They are hardly considered when developing disaster risk reduction strategies due to ignorance of disability, its causes, management and prevention, the needs of persons with disabilities and the need for them to be part and parcel of community undertakings. This renders them perpetual victims to disaster.

In the observation of rights, it is imperative that they are part and parcel of all community interventions. Disaster risk reduction is attained with capacity development for identification, assessment and reducing the likelihood of experiencing the massive loss of lives or property and destruction of the environment. It is about reducing socio-economic vulnerabilities to disaster as well as dealing with the environmental and other hazards that trigger them. Its scope stretches beyond the conventional emergency management and requirements.

In relation to disability, adoption of both the twin-track and whole community approaches is imperative. Disaster risk reduction can therefore be attained by empowering persons with disabilities, eliminating barriers to participation

and engaging all individuals, families, communities, organizations, service providers and all other stakeholders in society to work together for the common goal. Information, knowledge and skills provision facilitates capacity development.

Disability inclusive Disaster Risk Reduction (DiDRR) is increasingly recognized as an important component of community resilience in the event of a natural disaster as documented in the recent outcome of the 3rd World Conference, the Sendai Framework for Disaster Risk Reduction 2015-2030. It calls for enhancing the capacity of persons with disabilities to fully participate in, and contribute to, disaster risk reduction policies, programmes and practices and having all their needs adequately met.

The United Nations' commitment to persons with advancing equitable and inclusive development is deeply rooted in the Convention on the Rights of Persons with Disabilities (CRPD). Article 11 provides for the protection and safety of persons with disabilities in situations of risk, including the occurrence of natural disasters. Article 9 requires countries to identify and eliminate barriers and ensure that persons with disabilities can access their environment, transportation, public facilities and services, information and communications technologies. It is therefore necessary to develop inclusive disaster risk reduction strategies.

Developing Disability Inclusive Disaster Risk Reduction strategies

"The more governments, UN agencies, organizations, businesses and civil society understand risk and vulnerability, the better equipped they will be to mitigate disasters when they strike and save more lives": Ban Ki-moon, United Nations Secretary-General.

For **"no one to be left behind"**, disaster risk reduction strategies should be made inclusive. This will be attained using participatory learning approaches to harness existing knowledge and information to develop appropriate inclusive strategies. The approach fosters acceptance, ownership and sustainability.

The process starts with situation analysis to identify the various risks that exist in the community. The risks are prioritized and analyzed to establish the most pressing risk and its cause-effect relationship which informs development of an appropriate strategy.



Vulnerability and capacity assessment are undertaken to explore vulnerability and capacity as well as to scan the environment for resources, strengths, weaknesses, opportunities and threat to inform strategy development. With all this information, appropriate inclusive disaster risk reduction strategies are developed, implemented, monitored, evaluated and reviewed for sustainability.

Disability inclusive strategies cannot be developed unless community development personnel and all people working in disaster risk reduction acquire disability awareness and make it more inclusive for different country settings. Disability/Equality awareness may include; clear understanding of impairment and disability, types of impairments, needs and challenges for the various categories of persons with disabilities and barriers to their participation. They should also learn the social, economic, political, cultural issues and concerns which affect persons with disabilities, their families and community to inform the planning process. It is equally important to recognize the rights of persons with disabilities within the broader concept of equality for all members of society; and the use of appropriate language that is acceptable to them.

Conclusion

Disability inclusive development has been prioritized in the development agenda. This is evident in the Sustainable Development Goals to *“leave no one behind”*. Persons with disabilities are known to be highly vulnerable and have been victims of various disasters due to their limited capacity. In order for us to have a society that *“leaves no one behind”*, it is important to enhance their respective capacities together with disability awareness to facilitate their empowerment and enablement as currently advocated in Community Based Rehabilitation.

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CHAPTER 6

Community and Family Founded Education

Elie Bagbila, Katharina Pförtner***

Summary

Education rates high on the development agenda. Policies and strategies have been made to enhance the education system that promotes inclusive education where all children including those with disabilities access quality education. Inclusive education is the foundation to inclusive development which reflects the participation and commitment of all. As a social instrument, education must take root in the family and within the community. The family and the community are the heart of the education system for increased access to education for all the children hence the need for a community based approach.

Introduction

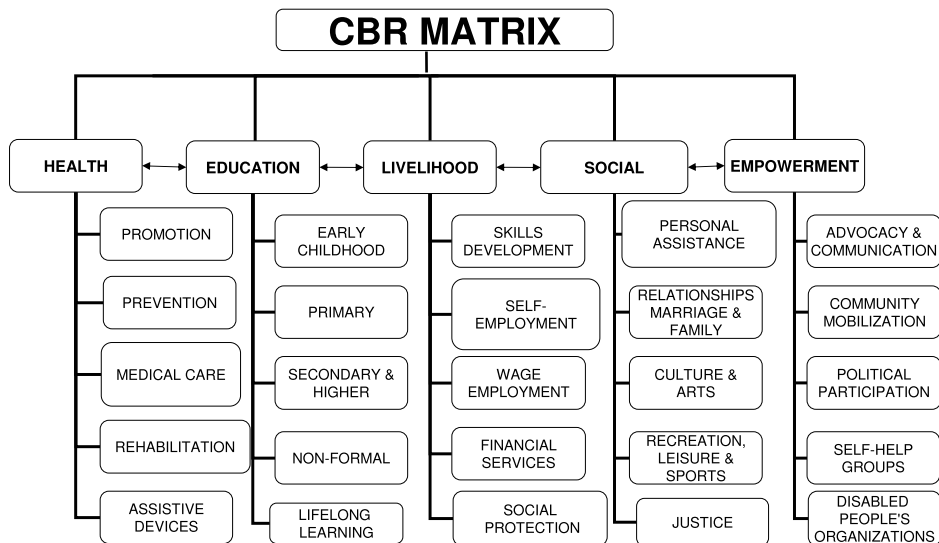
Universal education was the second Millennium Development Goal. By 2015, several countries in the world had not yet attained it. This is why, at the end of 2015, at Incheon in South Korea, the whole world committed itself to a new vision for education to be implemented by 2030 (UNESCO, 2016). This new vision finds its full expression in the 4th Sustainable Development Goal (SDG): *“To provide an inclusive and equitable quality education and promote life- long opportunities for learning for all”*.

The United Nations Organisation for Education, Science and Culture (UNESCO, 2014) estimates that 90% of children with disabilities from the low income countries do not go to school; and it is estimated that almost 30% of the world's street children are disabled. In order to include this outlying portion of the population in the educational systems, it is imperative to take action at the legislative level, so as to guarantee the right to education and work, and to make these systems inclusive; that is to say, apt and ready to manage diversity. The family and the community have an important role to play in this process. In order

to help the families and communities to play their role fully, Community Based Rehabilitation (CBR) should take centre stage position: *“working with the education sector and the communities to make education inclusive at all levels, and facilitating access to life-long education and training for disabled persons”* (WHO, 2010).

Inclusive education implies that all children can learn according to what they need and want in their life, based on their capacities. This includes “learning to know, to do things, to live together and learning ‘to be’.” Education intervenes within the family, the community, schools and institutions, and generally within the society.

The CBR Matrix



The main objective of inclusive education is to provide access to education and continued learning to all children with disabilities so as to guarantee their accomplishment, the development of their full potential, strengthening their self-confidence and dignity, as well as their participation in the community activities.

What could be the role of a CBR Programme in each sub-field?

Early Childhood: early intervention; door to door identification of children with disabilities; collaboration and work with the parents in developing the child's aptitude through simulations.

Primary Education: collaboration with the education system to work towards inclusion; help parents and children with disabilities to access education within their life community; develop and strengthen existing social links (home-community-school).

Secondary Education and Higher Learning: facilitation of inclusion, participation and scholarly success through a better access to instruction; work with school administration on improving accessibility and flexibility of teaching programmes and training.

Non-Formal Education: collaboration with non-formal education programmes to ensure that persons with disabilities have access to learning opportunities that are adapted to their needs and interests in the most inclusive manner possible.

Life Long Education: collaboration with professional training programmes, the community and the parents in order to avoid social exclusion, marginalization and unemployment of persons with disabilities through opportunities for continued training.

Barriers to Inclusive Education in Ordinary Schools

Although the roles of CBR programmes have been clearly defined and despite the existence of community commitment and the determination of the parents and children with disabilities, barriers to real inclusion in the educational system persist:

- Socio-cultural prejudices against persons with disabilities, concerning the intellectual capacity of children with disabilities to learn;
- The rejection or fear of other children and their parents as well as teachers with regard to children with disabilities (many think that the disability is contagious);
- The lack of care services and adaptations for children with disabilities;
- The non-adaptation of scholastic and training infrastructure;
- The incompetence or powerlessness of teachers and trainers who need to take charge of children with disabilities alongside other children (lack of training, lack of adapted material).

Involving the Community and Family in Education

Overcoming these barriers necessitates a strong involvement of the community and family in the education of children with disabilities and in the functioning of the educational system.

Local Committee to support education: this local committee is different from parent-teacher associations or any other structures supporting the education system. However, the committee will incorporate members of other community based organisations which support education development as well as ministerial structures (social action, the Municipality, decentralized structures of the Ministry of Education, etc.). The main role of the Committee is to ensure that there is inclusion of children with disabilities and to support the parents and teachers of these children.

Sensitization: Sensitization enables the creation of an environment that is conducive to the inclusion of children with disabilities in education and all other aspects of society. A population which is sensitized about the issues of disability, disabling diseases and the different possibilities and capacities for children with disabilities going to school, provides a basis for inclusion and access to quality education. Children with disabilities are better accepted in their community, the parents are more involved in the schooling and socialization of their children; children with disabilities are accepted by the teachers and fully participate in school activities including playing with their classmates.

Medical Care and Support: Many times, this is the entry point for change of attitude of the other children and members of the community. The community and family have to ensure that children with disabilities are well cared for and are beneficiaries of an adapted programme. This support, in terms of care services and functional adaptation, forms the base for individual and family awareness of the physical, intellectual psychological and other capacities of children with disabilities, enabling them to participate actively, in their own way, in social life and to access education.

Accessibility: This equally necessitates the involvement of the community and family in watching out for cases of inaccessibility. The community and family must ensure that this right which is indispensable to successful quality education is respected by all the actors in the education system: infrastructure and training must be adapted and accessible to children with disabilities. The community can do this if the frontline leaders of villages and communities take the issue

into account in their policies and/or strategies of development of their locality. This can vary from the simple construction of ramps to accessible classrooms in school, mobilization of local and external resources for building additional rooms, and other accessibility forms such as providing special teaching of Braille, sign language and other appropriate forms of communication for children with disabilities.

Training: The community and family must be involved in the training of teachers and teacher trainers; supporting children in class at the psychological level and socio-educational accompaniment, motivating teachers and trainers and also motivating fellow parents of children with disabilities.

The principle of life-long learning begins very early within the community, at home with the parents: training of parents with manuals, in self-help groups is instrumental in helping blind and deaf children at to learn communication as they prepare to come to school. It may also facilitate their respective capacity development in mobility and activities of daily living which all prepare them to access quality education.

Resolving Distance to School: Often, the problem of distance makes it hard for child with a disability to access even the nearest school. This can be resolved through the community and the family when they are involved and organized. Parents can be encouraged to provide means of transport for the children to go to school using adapted bicycles, tricycles and wheel chairs or other mobility supports and motorized or animal traction devices.

Recreational and Leisure Activities: The involvement of the community and family is indispensable for breaking barriers of taboos and facilitating a strong participation of the children in the development and demonstration of their sports talents, and in fun-filled activities.

Self-help Group: Through self-help groups, the community and families of children with disabilities can collectively carry out advocacy for education of their children, recruit and train volunteers and play a leadership role in inclusive quality education.

Motivation of Parents, Pupils and Teachers: can be done through the institutionalization of competitions for enrollment increment as a catalyst for the unconvinced, and performance assessment so as to improve school results.

Civil Recognition of the Child with a Disability: In many organized communities, the proof that a child exists with a civil status is manifested through a birth certificate. Unfortunately, this is not the common practice for children with disabilities. Access to a school for any child is upon presentation of that certificate of civil status. Only the family and community are involved in this responsibility.

Information on the Rights of Persons with Disabilities: Popularize the documents articulating the rights of persons with disabilities thus contributing to health care awareness and socio-professional approach to children with disabilities. The family and community are right at the core of this information.

CBR Approach with a Focus on Children with Disabilities

Implemented in the community with use of locally available resources, CBR facilitates identification and implementation of mitigation measures to minimize challenges for persons with disabilities. It facilitates empowerment and elimination of barriers in contribution to inclusive development. It is both a proactive and reactive approach. It is hinged on the advantage of precocious actions and interventions for children, whether disabled or not.

Roles of the family and of the CBR Programme:

- Sensitization of the community on disability and disabling diseases
- Identification of children with disabilities of all categories within the community
- Referring the identified children to specialized care structures for coverage
- Participation in the care for and adaptation of the children
- Assessment of aptitudes of children with disabilities for schooling or professional training or other purposes
- Counseling provided to the children, family and community on how to reduce or eliminate barriers to education
- Promotion of the right to protection for children with disabilities.

Conclusion

Etymologically, education is the action of ‘guiding out of’, that is, to develop, to make productive. Recently, it has come to mean the teaching and development of physical, psychological and intellectual capacities, as well as the means and results of this development activity. Teaching about life begins in the family and community before the child goes to school. It is therefore hard to imagine an

educational system which is founded outside the support and participation of the family and the community. The balancing, good performance and sustainability of any educational system call for the involvement of the grass-root community. That explains the necessity for us to ground our educational systems within the community and family for the highest success of scholarly and social inclusion.

As more parents insist on the right to quality education of their children with disabilities, a growing number of teachers will respond by identifying the best option for inclusion. The CBR Guidelines provide a starting point for schools, parents and the community to collaborate on education of children with disabilities within the local context and resources. Publication of good practices in inclusive education should be encouraged to convince others and ultimately lead to the formulation and implementation of an inclusive education policy by the Ministry of Education.

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CHAPTER 7

Making Higher Education Inclusive

Pascal Ahidjo, Paul Kamau Mbugua**, Victor Locoro****

Summary

Inclusive education was declared at Salamanca, Spain in 1994. Two decades since its declaration, the 5th conference of the CBR Africa Network organised in Nairobi, Kenya was an ideal opportunity for CBR practitioners to discuss issues related to inclusive education. This chapter highlights reflections on the contribution of CBR in making higher education inclusive. These reflections emerge mainly from the analysis of research studies carried out in Africa and the experiences shared during the conference. It is observed that besides personal factors related to type of disability, many other factors related to policies, attitudes, infrastructure, resources and communication make it difficult for students with disabilities to receive inclusive education in institutions of higher learning in many countries in Africa.

During the conference, it was noted that CBR can significantly contribute to making higher education inclusive especially by involving communities, supporting families, helping in the creation of an inclusive learning environment, encouraging the optimal use of resources, specialised support, and helping to facilitate transitions.

Introduction

Education is a key determinant of well-being. Prior to the advent of inclusive education, learners with disabilities accessed education in specialised schools. These mainly provided pre-school, primary and secondary education. Beyond secondary school, persons with disabilities were only able to access vocational training.

Following the declaration of Inclusive Education at Salamanca in 1994, many children with disabilities found their way to school and now access higher education. Despite the provision of universal primary education, transition

of pupils with disabilities from primary to secondary and from secondary to higher education has not been emphasised. There is a high rate of dropout of learners with disabilities at secondary school level and only a handful attains higher education. Disability actors are greatly concerned about access to higher education by students with disabilities.

This chapter clarifies some basic concepts, enumerates the challenges related to access by students with disabilities to higher education, and presents the contribution of Community Based Rehabilitation (CBR) and some strategies that can be adopted to promote inclusive higher education.

Education as a Concept

Education is the process of acquiring learning, or the acquisition of knowledge, skills, values, beliefs and habits. According to UNESCO (2000), everybody is able to learn what they need and what they want, during their entire lives, according to their abilities. This includes *“learning to know, learning to do, learning how to live together, and learning to be”*. Education according to UNESCO occurs in the family, community, schools and institutions. The universal right to education is inscribed in the international legal instruments acknowledged worldwide.

Dada and Eri-Olorunda (2014) defined higher education as an educational level that follows the completion of a secondary education such as a high school, secondary school or gymnasium. According to them, tertiary education is normally taken to include undergraduate and postgraduate education, as well as vocational education and training. Completion of tertiary education generally results in the awarding of certificates, diplomas, or academic degrees. According to UNESCO (2000), education is a human right for all throughout life and that access must be matched by quality.

UNESCO (2000) defines inclusive education as *‘a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision of ensuring accessibility to education for all children.’*

Inclusive education refers to the situation where all learners - with and without disabilities or difficulties - learn together in ordinary pre-school provision, schools, colleges and universities with appropriate networks of support. Inclusion

means enabling all learners to participate fully in the life and work of mainstream settings, whatever their needs. It is about eliminating barriers to accessibility and participation in learning for all children regardless of their individual differences (Miles et al. 2011).

Inclusive Education

Several international policies were drawn to promote education of persons with disabilities. Many of these influenced development of national policies especially for the UN member countries.

Having observed the exclusion of children with disabilities in education, the Convention on the Rights of the Child was declared in 1989. This policy highlighted the right of each child to education. In 1990 at Jomtien, “Education for All” was declared. This was aimed at promoting education of learners with disabilities who were still being excluded in many communities.

In 1993, 22 UN Standard Rules were declared and they spell out the factors that facilitate access of children with disabilities to education. The rules were comprehensive containing; preconditions for equalization (raising awareness, medical and rehabilitation service provision, and support services), areas that require equalization (accessibility, education, employment, culture and religion among others), and implementation measures (information and research, policy formulation, coordination of work and personnel training among others). All these details were necessary to ensure that both persons with disabilities and the system or environment in which they live are worked upon concurrently to ensure inclusion. Though not pronounced at that point, the twin-track approach was coming into existence. Twin-track approach is where efforts are made to prepare individuals and the environment at the same time so that by the time the people are ready to engage in activities the environment is favourable to enable them participate accordingly.

In 1994, inclusive education was declared at Salamanca to promote education of learners with disabilities in the mainstream. Persons with disabilities had initially accessed education in special schools and later in integrated schools where only a special unit was attached to a regular school to meet the educational needs for specific disabilities. Despite their contribution to education of persons with disabilities, these two provisions only accommodated a few learners since they were few and sparse. Inclusive education occurs in schools within communities.

All schools are mandated to have all necessary modification, facilities and competence in serving all children including those with disabilities, and having all their educational needs equally met.

Since then, several other policies have been drawn. Among these are the Dakar Framework of Action on Education for All (2000) and the United Nations Convention on the Rights of Persons with Disabilities (2006).

Each of these policies led to various national policies in different countries. However, most countries concentrate on education of children with disabilities in primary school with a low emphasis on secondary and higher education. This weak preparation for the transition between these levels of education exposes students with disabilities to several institutional, attitudinal, infrastructural, social and environmental barriers that slow down the pursuit of their studies on the basis of equality of chances with the other pupils.

Higher Education for Persons with Disabilities in Africa

During the 5th conference of the CBR Africa Network, efforts were made to explore higher education among persons with disabilities. Based on the available literature, several authors agree on the main barriers being: social and environmental factors such as financial challenges and barriers related to communication (Dada and Eri-Olorunda, 2014). These barriers bring to light the question of policies related to education (Kochung, 2011; Dada and Eri-Olorunda, 2014).

According to Kochung (2011), in African countries where human rights policies have been enacted, such policies only exist on paper and are hardly translated into practice. Most of these policies have no clear goals and defined principles, which ultimately makes it difficult for them to be implemented. As a result of inability to implement human rights policies, there is lack of interest in developing policies on higher education for persons with disabilities. For Kochung (2011), barriers faced by students before enrolling into higher education include:

- Social exclusion and stigmatisation by society.
- In many communities, most institutions of higher learning do not cater for students with disabilities.
- Inaccessible environment both in the communities to enable learners access education and within the institutions such that even when they are enrolled,

they experience barriers that force them to opt out of school. Environments where higher education institutions are situated are generally not accessible.

- Admission criteria to higher education institutions are complex, inflexible and stringent for vulnerable students intending to be enrolled.
- Most vulnerable students intending to enrol into higher education are from poor economic backgrounds. They can hardly afford the basic requirements needed by persons with disabilities to effectively participate and benefit from education.

Beyond these general barriers, there exist specific ones according to countries. Diverse studies report local constraints faced by students with disabilities at higher education level as detailed below.

Togo: Abi and Buan (2014) observe that the learning conditions of Togolese pupils and students are always on headlines every academic year following strike actions demanding better services and provisions. The difficulties faced by some pupils and students with disabilities in Togolese education institutions are not well known. In a study undertaken by Visions Solidaires and CBM, Badabadi and Ali (2014) noted that the difficulties relate to the accessibility to school and university infrastructure, their orientation at the secondary level and after the advanced level, the quality of the services offered by some supporting structures at their disposal, and negative attitudes experienced from the university staff and their peers.

According to Abi and Buan (2014), most schools having learners with disabilities are not equipped with accessible toilets. These are a basic requirement for learners with movement challenges. Facilities are also not adapted to suit individuals with different types of disability. The large numbers in the classrooms also make it difficult for students with disabilities to access seats even when they struggle to access school.

Most institutions of higher learning lack appropriate technology and facilities especially those required by persons with hearing impairment and visual impairment. The situation is even more difficult when students with visual impairment who fail to access seats close to the chalkboard have to cope with the noise made by the large number of classmates; some lecturers write on the board without reading what they write. This is due to the wide knowledge and information gap on the needs of different categories of persons with disabilities.

Only a few learners with disability know the support structures and facilities that

exist to help them access education. These structures and facilities are very few and under-financed. Academic and professional orientations that exist do not take into account the different types of disabilities.

Burkina Faso: In a study on the state of Inclusive Education in Burkina Faso, Afrik Consulting (2013) noted that the socio-economic and politico-administrative context of Burkina Faso is not yet favourable to develop sustainable inclusive education. Many children with disabilities are still locked up in communities far from school, and the negative attitude that still prevails deprives them of opportunities to build their future. These results from lack of tools and knowledge required to integrate them in the society. In the interventions carried out by many actors from civil society, there exist technical and pedagogic constraints. These constraints according to the same study include; lack of logistics and didactic materials, inadequate infrastructure, insufficient human resources, inappropriate education programmes, lack of assistive devices, inaccessibility, unmodified education system and negative attitudes among parents and service providers.

Under such circumstances, it is inevitably difficult for learners with disabilities to access and survive through primary and secondary school education and attain higher education. Only a few of them, especially those with mild movement challenges have accessed higher education.

Kenya: Despite the embracing of universal primary education and universal secondary education, access to higher education is still a challenge as reported by Kochung (2011). The lack of universal secondary education minimizes access to higher education since many learners drop out along the way, partly due to inadequate resources, lack of appropriate facilities, trained personnel and poor prioritization at family and community level. Kochung reported that the political, social and economic structures in Kenya do not favour inclusion in higher education. The structures are discriminatory, and exclude vulnerable members of society especially those coming from poor families and those with disabilities. For Aletheia (2015) the problem starts in secondary education. Indeed secondary school is still out of reach for many; the costs associated with secondary school remain a barrier for many students, but in particular for the most marginalised.

Among the barriers faced by students with disabilities in Kenya are:

- Negative attitude of teachers and stakeholders
- Unmodified and rigid instructional methods, examination systems and curriculum in higher education

- Lack of resources including trained personnel, limited community involvement and inadequate funding.
- Education in universities and colleges is not free and the cost is far above the ability of ordinary citizens
- Lack of policy on inclusion

Cameroon: A study conducted by ROCARE/ENRWACA (2008) concluded that difficulties faced in the education of children with disabilities in Cameroon are as numerous as the causes of disability.

- Students with disabilities are despised and denied opportunities for competition even when they are well qualified.
- Parents discriminate children with disabilities considering them to be “useless” to the family and society and therefore not worth the investment.
- Teachers hardly meet the educational needs of children with disabilities partly due to negative attitude, ignorance and due to lack of pedagogical skills.
- There is lack of appropriate educational materials and assistive devices. Even when available, they are very costly, beyond the means of the marginalised poor.

Nigeria: A study carried out by Dada and Eri-Olorunda (2014) in Nigeria revealed that several factors limit the access of students with disabilities to higher education. The study reported that social and environmental factors determine education of students with disabilities. Negative attitude of other students and teachers towards persons with special needs are prominent especially due to ignorance of the need for persons with disabilities to acquire education. The study also revealed that communication barriers limit access to higher education by persons with disabilities.

The right to secondary and higher education for children with disabilities is underlined in the United Nations’ Convention on the Rights of Persons with Disabilities (Article 24, paragraphs 2(a), 2(b), and 5) (4). WHO (2010) reports that in several poor communities, only few students with disabilities have access to secondary and higher education. In many poor economies, education is beyond the reach of many and students with disabilities are completely excluded or have to face a constant battle to prove their abilities.

Uganda: Inclusive education was adopted in 1997 along with universal primary education. Though various challenges are encountered, efforts are in place to facilitate access to higher education by persons with disabilities.

Kyambogo University was established in 2003. The institution was formed from a merger of three academic institutions: Institute of Teacher Education Kyambogo, Uganda Polytechnic Kyambogo and Uganda National Institute of Special Education. From inception, the University was mandated to develop and promote programmes aimed at fostering inclusive education and training, comprehensive rehabilitation service provision and empowerment of persons with disabilities and other special needs at all levels in the country (Government of Uganda, 2003). Since then, Kyambogo University and particularly the Faculty of Special Needs and Rehabilitation has worked closely with government and civil society stakeholders in the pursuit of this mandate.

Higher Education in Uganda

According to UBOS (2012) and AYDU (2014) approximately 1,000 students with disabilities qualify at high school level to join higher education annually and about 60% of them get enrolled in institutions of higher learning for certificate, diploma and degree courses.

In 1989, Uganda adopted affirmative action for the girl child. Girls are accorded 1.5 points as affirmative action at the different levels of national examinations including higher education. In 1998, affirmative action was also adopted for students with disabilities who do not get admitted on merit to institutions of higher learning. 64 bursary places are reserved for persons with disabilities who are in this category so as to access higher education. They are given application forms on the “disability ticket” which they submit to the relevant department in the Ministry of Education. Qualification is based on academic performance to fill all 64 places in the various public institutions of higher learning. Despite this move to increase access to higher education by persons with disabilities, many students with disabilities experience challenges.

In Makerere University, sighted guides or readers, sign language interpreters and specialized equipment and materials such as Braille paper are not provided hence making it difficult for students with visual impairment and hearing impairment to access and benefit from education. In some cases, students are provided funds to purchase the required equipment which is sometimes not readily available in the market. In many other institutions of higher learning, such opportunities and facilities are not available. Their only alternative is to rely on occasional support from non-governmental organizations.

The unfriendly physical and learning facilities in both universities and tertiary institutions in the country also restrict active participation of students with disabilities. This is largely attributed to:

- Ignorance of the needs of persons with disabilities, the barriers they experience and the need for them to participate in education at all levels
- Inadequate implementation of relevant policies and legislation
- Limited funding for services and facilities required by persons with disabilities and those with other special needs
- Limited inclusion of disability issues in institutional policies and planning
- Limited use of appropriate technology to facilitate learning for students with disabilities
- Limited trained personnel in relevant specialized service areas to guide institutions and provide the necessary services and facilitate accessibility
- Lack of rehabilitation and limited provision of assistive devices and other specialized materials and facilities required by students with disabilities.

As a result of the nationwide advocacy by the Disability Movement stakeholders both in Uganda and internationally, the increasing recognition of the social model of rehabilitation and the human rights-based approach to service provision, a number of legislation, policies and programmes have been established by government to promote access, equity and quality of education and training for persons with disabilities at all levels. Kyambogo University trains personnel in special needs and inclusive education, comprehensive rehabilitation and empowerment of persons with disabilities, families and communities.

All university students in the Faculty of Special Needs and Rehabilitation have community practice according to their respective courses. During community practice, the students enhance their knowledge and skills while providing free services to persons with disabilities, families and communities. This greatly facilitates effective learning and actualization of content with great hope for ownership and sustainability at family and community levels.

CBR for Inclusive Higher Education

Community Based Rehabilitation (CBR) is a community development strategy aimed at empowering persons with disabilities and enabling them to actively participate in all aspects that concern them. It enhances their participation at

individual, family and community level. CBR is therefore an appropriate strategy which can be effectively utilized to promote education among persons with disabilities. CBR involves use of locally available resources, including persons with disabilities, their families and communities to enhance lives and promote inclusion.

CBR is implemented through collective effort with several stakeholders. It advocates for disability mainstreaming and elimination of barriers. Implemented within the community, CBR facilitates acceptance, ownership and hence sustainability of interventions. It is therefore necessary in promoting inclusive higher education.

In promoting inclusive development, CBR encourages use of both the twin-track approach and community development approach. This is based on the contention that “it takes two to tango”. Empowerment and enablement are both required for successful inclusion. Making higher education attainable by persons with disabilities requires adoption of CBR and the basic requirements set out for inclusive education at inception in Salamanca in 1994.

Suggestions to promote inclusive education

Staff Preparation

Higher education cannot be disability-inclusive unless we have competent staff with favourable attitudes to effectively meet the needs of persons with disabilities. It is therefore necessary to raise awareness on disability, its causes, management, the respective needs of persons with disabilities and the need for people with disabilities to participate and access education. This will greatly help to demystify disability and facilitate change of attitude.

It is equally necessary to train teaching and non-teaching staff in appropriate communication and other basic service provisions for the various categories of persons with disabilities.

Student Preparation

Without adequate preparation of the students, preparation of the institutions alone will not actualize inclusion. Preparation of students starts with provision of rehabilitation services, appropriate assistive devices, modifications and

provisions to enable children with disabilities access early childhood education, primary school education and secondary school education, for them to qualify for higher education. That is why adoption of the twin-track and whole community approach is important.

Raising awareness is important, starting in the families and communities to understand disability, the needs of and the need for, persons with disabilities to engage in individual, family and community activities. Awareness is also necessary for the students without disability to understand disability, the need for them to work together with students with disabilities, share learning and support each other for growth and development. Students with disabilities equally need awareness and guidance to develop favourable attitudes for successful inclusion.

Appropriate Modification

Considering the diverse needs of persons with disabilities, various modifications, facilitating efforts and provisions are necessary to promote inclusion. The environment needs modification with ramps and landmarks, buildings with ramps, sufficient lighting, wide doors, toilet rails, rails on staircases and walkways in buildings, and all other facilities required for various types of disability. There is equally a need for provision of Braille and large print materials to enhance access to information by persons with visual impairment, need for sign language interpreting services for those with hearing impairment and pictorial communication charts for those who have intellectual challenges. In this world of Information and Communication Technology (ICT), computers and all the various ICT required by persons with disabilities should be availed by the institutions of higher learning to promote inclusion.

Curriculum Adaptation

Adaptation of curriculum content and implementation methodology is essential for ensuring that all students benefit from the same learning environment and session. Study materials and other resources should be provided in large print, Braille and/or audio format for students and staff with visual impairments.

Currently Kyambogo University runs a small resource centre for students with visual impairments. The centre provides support towards production of students' study materials in accessible formats. It has a closed circuit television (CCTV) and

computers with speech screen readers which facilitate the students' study and writing of examinations. The centre also provides guidance to other universities in the country where some students with visual impairments are enrolled.

In a few instances, students with recent vision loss who have not yet acquired Braille skills, have benefited from provisions such as recording devices to help them follow lectures and keep recordings as reference material. In such cases, their exams are written for them as they respond to questions accordingly. The same applies to students with severe dyslexia and those with weak muscles who cannot write on their own.

The university has put in place an institutional policy on disability to enable it translate the National Policy on Disability in Uganda (2006) into practice. The institutional policy is required to guide the university in matters relating to budget allocation for the needs of students and staff with special needs, admission of and examinations for students with special needs, their accommodation, feeding, recreation, employment, and career development and job retention of staff with special needs.

The institutional policy also provides for the establishment of a Special Needs Assessment Committee which is responsible for identifying and assessing the study, mobility and welfare needs of students with disabilities and recommend appropriate interventions.

Support Services

To enhance accessibility to learning by students with disabilities, support staff is required to meet the various needs of students especially those with visual impairment and hearing impairment. Among the support staff are: sign language interpreters, sighted guides/readers, wheel chair guides and personal assistants in the case of students with severe motor and multiple impairments. Other essential support services include: motorized transport within the institution to ease mobility of students with disabilities who need it; guidance and counselling services to facilitate change of attitudes, adapted games and sports and collaboration.

Since we live in a world of limited resources, there is need for networking and collaboration with various stakeholders in the disability sector, education and community development. This helps in resource mobilization and effective utilization of resources and available facilities to make inclusive education cost-effective and sustainable.

Employment of Persons with Disabilities

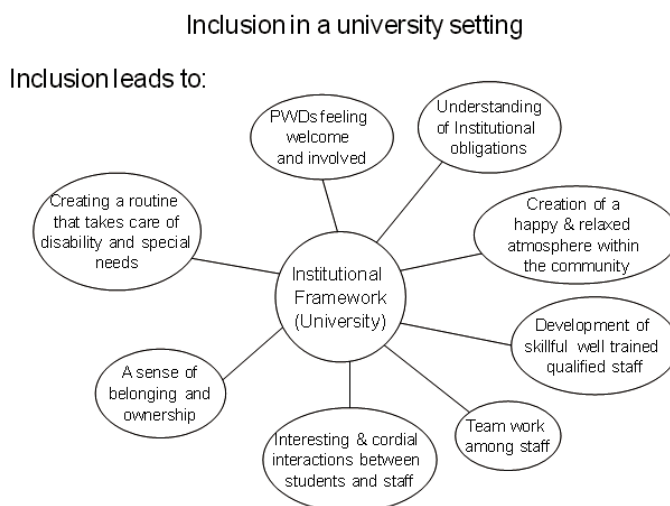
The ultimate aim of education is to increase livelihood opportunities. Persons with disabilities need a ray of hope for employment to get inspired into education to the higher levels. In an academic institution like Kyambogo University, teaching and non-teaching staff serve as role models both for students with disabilities and many people with whom they interact in the various communities.

In many instances, persons with disabilities prefer employment in their respective circles and this restricts awareness creation to change attitudes both among persons with disabilities themselves and among community members. Inclusive education was introduced to create a favourable ground for inclusive development. As long as awareness is raised, attitudes are improved, and necessary modifications are made, persons with disabilities can effectively compete for employment and serve as models among others in their respective communities.

Persons with disabilities will access higher education in any community as long as there is awareness, favourable attitudes, policies, policy implementation and effective monitoring and evaluation. This requires adoption of both the twin-track and whole community approaches as well as commitment of resources by various stakeholders.

Benefits of Inclusion

The figure below highlights some benefits of inclusion in a university setting.



The CBR Guidelines WHO (2010) details the contribution of CBR to inclusion of persons with disabilities in all circles of education. The Guidelines recommend the following:

Community involvement: by encouraging community members and local authorities to mobilize support, in this case, to higher education especially by advocating for scholarships and lowering admission points to increase access.

Support families: by training family members or by providing support such as income generation projects to enable the family to provide fees and assistive devices to students with disabilities.

Help in the creation of an inclusive learning environment: (i) by emphasising on the environment and the position of lecture halls and laboratories, (ii) by adapting pedagogic programmes and methods in order to make them inclusive, (iii) by making examinations and assessment systems more flexible and adapted to respond to the needs of all students, (iv) by watching out for the adaptation of information and communication technologies and (v) by encouraging the support of peers and role models.

Encourage best use of specialist resources and support: CBR has to encourage specialised institutions to continue to play their role in support especially by providing personal assistants or temporary lecturers in order to support students with disabilities.

Help to facilitate transitions: Kochung (2011) signals that students with disabilities who register for higher education are meant to come from secondary schools; however, in most African countries, especially Sub Saharan countries, students with special needs are vulnerable and scarcely complete their secondary cycle of education, and even if they complete, they are not able to meet all registration conditions that are based on academic performance and economic ability. It seems urgent to prepare for the transition between the two educational levels. Lederman (2005) notes that *“by reason of the difficulties during the transitions, research shows that twice the number of students with disabilities does not succeed in pursuing their university studies contrary to their peers”*. Also WHO in the CBR Guidelines, suggest to CBR programmes to collaborate with the students, their families, the members of the community and schools in order to ensure that positive ties are created and sustained all through the transition periods.

According to CBM (2011), regarding the education component, CBR makes a difference in the lives of community members, especially persons with disabilities, by focusing on the entire life experience, from early childhood to schooling

to lifelong learning. Examined from this angle, CBR can contribute in making higher education more inclusive if intervention begins from early childhood. A presentation by Katarina Pfoertner in the course of the Fifth conference of the CBR Africa Network shows how inclusive education can be implemented from early childhood. In the presentation, Pfoertner (2015) underlines that the CBR approach is a proven strategy for the realisation of the rights of people with disabilities. In Nicaragua, CBM has employed this approach to help children with disabilities gain access to the regular education system. The idea is to work in the local context and support children in an integrated way by involving the family, the community and all relevant institutions. In addition, children with disabilities often require medical care or support through special aids.

During the process some lessons were learnt, the most prominent was, *'Inclusion begins right after birth with early detection, early education and a referral system'*.

Lack of access to ICT at higher education limits independent learning and research. ICT should therefore be introduced to students with disabilities at primary level and should be available to them in higher education institutions. Advanced ICT skills of graduates with disabilities will increase their marketability.

Conclusion

CBR is an important tool for making the education system more inclusive through building collaboration between different education levels. The objective as mentioned by the CBR Guidelines is that: *'students with disabilities have the opportunity to learn with others and to acquire qualifications, competences and experience, as such facilitating the chances of acquiring their means of livelihood, autonomy ('empowerment'), and their inclusion'*.

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CHAPTER 8

Bridging the Gap for Women with Disabilities Through CBR Guidelines to Achieve Sustainable Development Goals: “Let’s Not Miss The Boat”

Elly Macha, Patience O.Dickson**, Jane Kihungi****

Summary

Gender-based violence reflects and reinforces inequality between men and women and compromises the health, dignity, security and autonomy of its victims. It encompasses a wide range of human rights violations, including abuse of children, rape, domestic violence, assault and harassment, trafficking of women and girls and several harmful traditional practices. Any one of these abuses can leave deep psychological scars, damage the health of women and girls affecting their reproductive and sexual health. In some instances it results in loss of lives.

Introduction

Persons with disabilities are the world’s largest minority. Approximately 15% of people worldwide are persons with disabilities, and women with disabilities account for 19.2% of the total population of women around the world, according to the World Report on Disability (2011). One in five women worldwide lives with a disability and the prevalence of disability is actually higher among women than men that is; 19.2% and 12% respectively. 80% of this population lives in developing countries, (WHO 2011).

Women and girls with disabilities are subjected to multiple layers of discrimination

based on their gender and disability status. This inequality is exacerbated for women and girls with disabilities who are members of marginalized ethnic or racial groups.

This chapter deals with basic facts; the legal framework; the critique; how ready for seafaring are women and girls with disabilities; and how to catch the boat. The central idea to be explored is posed in this key question: are women and girls with disabilities ready for seafaring on the “boat” of the Sustainable Development Goals (SDGs)?

Basic Facts

In order to establish why women and girls with disabilities need to be positioned now so that they do not miss the boat, it is imperative to critically look at how they have been faring socially, culturally and economically. Women with disabilities experience multiple disadvantages on account of gender and disability and other social, cultural and economic factors. By looking at the three dimensions of the SDGs: socio-cultural, economic and environmental, the following picture is painted describing this subgroup.

a) Socio-Cultural and Health Considerations

Women in general are seen primarily as having nurturing roles in society, including those of mothers, wives, and sexual partners; roles that are usually unpaid, onerous, and time-consuming, thus limiting their participation in social life. Moreover, such work is not valued in economic terms, which disempowers women. Women’s limited participation in the paid labor force results in their limited power and influence in decision-making both at home and in the community. Consequently, this leads to and reinforces negative stereotyping. Women in general, especially in developing countries, are seen as weak and vulnerable compared to their male counterparts, mainly due to cultural and social practices and beliefs that consider men as superior. In the same way, women and girls with disabilities are seen to be more weak and vulnerable as a result of their disability and this negatively affects their rights and privileges as citizens.

The situation is far worse for women with disabilities who experience a high incidence of physical, emotional, and sexual abuse including rape, incest and sexual molestation in their everyday lives, and they are much more likely to be victims of sexual assault and violence than their male counterparts. Any one of

these abuses may leave deep psychological scars, damage their physical health, including their reproductive and sexual health, and in some instances, result in death.

Once abused, in many cases, members of this extremely vulnerable group do not report the matter for fear of losing the support that they may receive from the abusers whether financial or physical. In the case of rape, women and girls with disabilities are easily targeted due to their vulnerability. Perpetuators assume the blind cannot identify them, the deaf cannot speak, the physically impaired persons cannot run or otherwise fight off the attacker, and the intellectually impaired cannot comprehend.

Women and girls with disabilities experience more discrimination and live in more disadvantaged conditions than their male counterparts. In some cases, women with disabilities do not have control over their lives. Those in the developing world face “triple jeopardy” as they are discriminated against on account of gender, disability, and geographic region – the developing world. This is exacerbated by the negative perceptions and prejudices relating to disabilities. For example, they may be regarded as asexual and thus denied opportunities to fulfill standard women’s roles such as wife, mother, and/or sexual partner in society, which limits their life choices and denies them self-actualization. Impairments of women are seen as limiting in terms of performing prescribed gender roles. Such disadvantages are exacerbated by lack of access to sexual education.

Further, women and girls with disabilities face disproportionately high rates of gender-based violence, rape and other forms of sexual abuse, neglect, maltreatment and exploitation, including domestic violence, the trafficking of women and girls and harmful traditional practices. The World Health Organization estimates that 35% of women worldwide have experienced either physical and/or sexual intimate partner violence, or sexual violence by a non-partner at some point in their lives. However, some national studies show that up to 70% of women have experienced physical and/or sexual violence from an intimate partner in their lifetime (WHO, 2013).

Women and girls with disabilities face coercion from healthcare providers regarding their reproductive decision-making. Women with disabilities are more likely to have hysterectomies at a younger age and for a non-medically necessary reason, including by request of a parent or guardian (Julia and Rivera 2013).

Women and girls with disabilities are often denied reproductive healthcare and at times are even subjected to forced sterilization; they may not physically access healthcare services where available or healthcare providers do not know how to accommodate them; many have little hope of having families of their own.

To make matters worse, the voices of women and girls with disabilities on these and other matters are often not heard and they have less opportunity to participate in decision making. In many cases, this vulnerable group may not even be aware that they have rights and that these rights are being violated; they may not be aware that they are entitled to respect of their inherent dignity. Moreover, women with disabilities are heavily constrained from becoming leaders within their communities and contributing to economic development despite their ability to do so (CEDAW, 1991).

b) Economic Considerations

Women with disabilities experience systemic and attitudinal discrimination in the livelihood arena on two fronts: firstly gender, and secondly as a function of their bodies. Therefore, they are multiply disadvantaged in this regard.

75% of women with disabilities are unemployed, and those employed often earn less than their male counterparts and women without disabilities. Gender disparities in education indicate that the overall literacy rate for persons with disabilities is 3%, whereas it is 1% for women and girls with disabilities. This group is more likely to be denied their right to an education both by the fact that they are girls and even worse because they have a disability (CEDAW 1991).

People worldwide who have less than USD 1.99 purchasing power parity (PPP) a day are graded as living below the extreme poverty line. Those who have a PPP of less than USD 8 a day are rated as living at the bottom of the economic pyramid, and hence are prone to being pushed into an extreme poverty pendulum by shocks/vulnerability such as the rapid onset of natural disasters, outbreak of conflicts, unabated prolonged economic recession, etc. Situations of this kind are caused by factors including: malnutrition, poor sanitation, lack of electricity, inadequate education opportunities, time poverty (spending more time on unpaid household and assistance activities), poor living standards, poor health care services, etc. These are said to be derivatives of socio-economic exclusions driven by economic, social and cultural factors that lead to inequality of outcomes and opportunities. Arguably, a majority of women with disabilities by all parameters fall under this economic spectrum.

c) Environmental Factors

People with disabilities, especially those with mobility challenges, visual impairment, and multiple disabilities experience accessibility challenges due to the many barriers that exist in society. Such environmental barriers caused by architectural oversights, ignorance, prejudiced mindsets or natural topographies, limit or prevent the participation of people with disabilities in social, economic and political life (CEDEW 1991). But the situation for women with disabilities in this regard is compounded by economical and socio-cultural factors as succinctly presented by the following excerpt.

When I got pregnant I was happy but my family was angry. They talked to the man responsible. He was a married man and accepted to look after me as a second wife. There was no kwanjula (traditional marriage ceremony) but I did not mind because he looked after me. He built a house for me near my parents' home. I went to hospital only once (during the pregnancy). It was expensive because I had to pay transport for myself and my sister who accompanied me. No I did not take the wheel chair. It would have been more expensive in the taxi and difficult to use. The hospital has steps so I prefer to crawl. In the hospital the nurses were good but said they could not examine me seated in the chair. My sister was helped by a man to lift me to the bed where I was examined. No, I did not need to use the toilet. When I go to hospital I do not drink water or tea so that I will not need to use the toilet. I delivered at the traditional birth attendant. It was easier for me and closer to home. It was also cheaper. At the traditional birth attendant you deliver on the floor. My husband gave the traditional attendant a goat (NUWODU 2009).

The various forms of oppressions women with disabilities face reinforce each other, resulting in unequal opportunities when compared with men with disabilities. The above shows us that women and girls with disabilities are among the most marginalized group in society. *"Girls and women of all ages with any form of disability are among the more vulnerable and marginalized of society. There is therefore need to take into account and to address their concerns in all policy-making and programming. Special measures are needed at all levels to integrate them into the mainstream of development"* (UN 2000). Their challenges not only affect them but also carry heavy financial and social consequences such as hindering economic development, limiting democracy, and eroding societies.

“The consequences of deficiencies and disablement are particularly serious for women. There are a great many countries where women are subjected to social, cultural and economic disadvantages which impede their access to, for example, health care, education, vocational training and employment. If, in addition, they are physically or mentally disabled, their chances of overcoming their disablement are diminished, which makes it all the more difficult for them to take part in community life” (UN 1982).

In order to better comprehend the current international agenda, we need to also remind ourselves of some associated concepts and catchwords.

Development is not purely an economic phenomenon but rather a multi-dimensional process involving reorganization and reorientation of the entire economic and social system. According to Todaro and Smith (2011), development is process of improving the quality of all human lives with three equally important aspects. It is therefore a process that involves a progressive transformation of economies and societies, that is, satisfaction of at least basic human needs (food, clothing, shelter, jobs) and aspirations for an improved quality of life as its major objective.

Sustainable development recognizes that growth must be both inclusive and environmentally sound to reduce poverty and build shared prosperity for today’s population and to continue to meet the needs of future generations. It is efficient with resources and carefully planned to deliver both immediate and long-term benefits for people, planet, and prosperity (World Bank 2013). As the concept developed, it has shifted to focus more on economic development, social development and environmental protection for future generations. The term sustainable development refers to the holistic approach and temporal processes that lead us to the end point of sustainability (Shaker, 2015). It requires societies to meet human needs both by increasing productive potential and by ensuring equitable opportunities for all.

Equity, although a malleable concept, is not legally binding. However, it is the moral imperative to dismantle unjust differences based on principles of fairness and justice. It requires a focus on the most disadvantaged and the poorest. It involves trying to understand and give people what they require to enjoy full, healthy lives.

Inclusive society is the one where all people feel valued, their differences are respected, and their basic needs are met so they can live in dignity.

The contemporary unanimously agreed definition of 'Community Based Rehabilitation' (CBR) is that: *"it is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and nongovernmental health, education, vocational, social and other services"* (WHO 2010).

United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides the human rights framework for the empowerment and realization of the rights and development of women and girls with disabilities as both agents and beneficiaries of development and humanitarian action.

Article 3 of the Convention outlines these general principles: respect for inherent dignity, individual autonomy including the freedom to make one's own choices and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Furthermore, Article 6 of the CRPD is specific to women with disabilities and underlines the recognition of women and girls with disabilities as being subject to multiple discriminations; it calls for measures to ensure their full and equal enjoyment of all human rights and fundamental freedoms; and the full development, advancement and empowerment of women for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the convention.

The CRPD also mandates state parties to ensure the protection and safety of women and girls with disabilities and those in situations of risk and humanitarian crises.

The Critique

The Boat of the SDGs

The year 2015 is memorable in world history as the end point of the Millennium Development Goals (MDGs) and the point of departure for the global flagship called the Sustainable Development Goals (SDGs), which are intended to curb the abominable living standards of the world's poor, and continue the work of the bygone worldwide roadmap such as the MDGs. The SDGs and associated targets came into effect on 1st January 2016 and will guide development decisions taken globally and nationally over the next 15 years. The SDGs pledge to, among other things: leave no one behind; seek to realise human rights of all; and achieve gender equality and the empowerment of women and girls. They envisage a world in which every country enjoys inclusive and sustainable economic growth and decent work for all. The SDGs therefore are divided into the following tiers: economic, social-cultural and environmental.

The new Agenda builds on the MDGs and seeks to complete what they did not achieve, particularly in reaching the most vulnerable and therefore those in most need of empowerment. One of the key failures of the MDGs is that disability was not mentioned at all, and so action and focus on persons with disabilities, and specifically women and girls with disabilities, was excluded. They missed the first boat. A positive outcome from this, however, was that organizations working in the field of disability came together to discuss and promote issues affecting persons with disabilities.

The SDGs have been made inclusive. They target the most vulnerable including all children, youth, persons with disabilities (of whom more than 80% live in poverty), people living with HIV/AIDS, older persons, indigenous people, refugees, internally displaced persons, migrants and others affected by humanitarian crises. The SDGs encourage countries to take further effective measures and actions, in conformity with international law, to remove obstacles and constraints, strengthen support and meet the special needs of people circumstantially restricted at the bottom of the social ladder. It is therefore clear that the SDGs are the very boat women and girls with disabilities must not miss.

As opposed to the MDGs that excluded disability, various parts of the SDGs refer to disability in general, and more specifically in the parts relating to education, economic growth and employment, inequality, accessibility of human

settlements, as well as data collection and monitoring of the SDGs, for instance in Goals 4, 8, 11 and 17. However, aside from some allusions, there is no single goal or strategy that categorically mentions women with disabilities. Therefore one can safely argue that the architects of the SDGs failed to take into account the well known fact that women with disabilities experience multiple disadvantages as females, people with disabilities and being the poorest of the poorest. This is often worsened by other aspects such as race and displacement among others. Therefore, women with disabilities are multiply disadvantaged in their struggle to board the SDGs boat.

Are Women with Disabilities Ready for Seafaring?

This is an important question that needs to be answered sincerely. Such a need emanates from the fact that in some ways, knowingly or unknowingly, women with disabilities share the blame for not participating when issues of grave concern were being discussed. There were many platforms that deliberated on the MDGs, which informed the drafting of the SDGs. It is worth asking how women with disabilities raised their concerns during the discourse. The prevalence of the barriers described above, which are acknowledged, should not be an excuse for the failure to grasp the opportunity that was available for all to seize.

For some time now, all development plans globally and nationally have revolved around internationally agreed upon and popularized themes. If the same are silent about women with disabilities, on what have we based our demands to different decision-making organs?

Could it be that all along we have been in a slumber and that is why it is only now that we are calling for specific inclusion in the SDGs?

Remember, it takes two to “Tango”. All solutions to this plight lie in the hands of the women with disabilities.

Can we catch the boat?

How to Catch the Boat?

Presumably, the SDGs are the boat in which women with disabilities intend to sail towards a barrier free and prosperous future. Some oars that can be used to row that boat are given below.

Community Based Rehabilitation (CBR)

1. CBR interventions that promote rehabilitation, equalization of opportunities and social inclusion of all people with disabilities if established or scaled up, could be an entry point for women with disabilities to get better oriented and ultimately assert themselves for social transformation.
2. CBR programme designs should address discrimination related to disability, and specifically women and girls with disabilities.
3. CBR implementers should develop programmes specifically geared toward the elimination of gender-based violence against women and girls with disabilities. These programmes should include building and strengthening legal capacities of women with disabilities to enable them seek justice. It is equally important to educate and strengthen the capacities of judicial systems and service providers in the area of recovery of abused women. Similarly, it is important to address barriers that hinder women and girls with disabilities from accessing justice.
4. There is great need to mobilize and educate communities to start supporting women and girls with disabilities.
5. CBR players must engage with women and girls with disabilities in humanitarian crises because no government will achieve the SDGs if a section of the society is left behind. CBR should strive to include in a more meaningful way organizations of women with disabilities because these can play a critical role in bridging the development and humanitarian divide, and also in strengthening community resilience.

Goal V: Gender Equality and Empower All Women and Girls

Sustainable Development Goal number five is “Gender equality and empowerment of all girls”. In order to have sustainable development, all members of the society or community, including women, must be involved in the development process, which includes women with disabilities. This is universally recognized in the UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). Women with disabilities must have a stake in all facets of development. Thus all developmental policies, strategies and plans must be inclusive and this must be seen as a right of, and not privilege to, girls and women with disabilities.

States must ensure the implementation of programmes that target the reduction or eradication of poverty for community women, which is the main area where

one finds many women with disabilities. It is important to legally prohibit, and strengthen laws and practices, against sexual and gender based violence in both rural and urban communities.

There is a need for an affirmative action in law and in practice for women with disabilities by states that are yet to legalize such policies, as stated in CEDAW, to increase the visibility of women with disabilities in appointed and elected positions.

Procedures and policies should be changed to ensure that women and girls with disabilities do not suffer due to the fact that they have disabilities. More so, institutional frameworks should be strengthened for effective implementation of laws and policies that protect and promote the inherent human rights of women and girls with disabilities. Further, there must be an increase of the allocation of resources to ministries in charge of women's affairs and rehabilitation and at all levels of governance, so that ministries effectively deliver on their mandates.

Networking

It is important that individuals and organizations of women and girls with disabilities come together as networks to more effectively advocate for the inherent human rights, dignity, respect and emancipation of women and girls with disabilities at all levels: locally, nationally and internationally. This will ultimately increase the voice, visibility and inclusion of women and girls with disabilities and improve their social and economic welfare. Participation in decision making at all levels of societal and political life is key if we are to achieve the total inclusion of women and girls with disabilities.

Conclusion

The boat to be caught is already in full motion, so jumping on board requires extra efforts by women with disabilities. As stated by Steve Biko:

"...This is the first truth, bitter as it may seem, that we have to acknowledge before we can start on any programme designed to change the status quo. It becomes more necessary to see the truth as it is. If you realise that the only vehicle for change are these people who have lost their personality. The first step therefore is to make them come to themselves, to pump back life into their empty shells, to infuse them with pride and dignity, to remind them of their complicity in the crime of allowing themselves

to be misused and therefore letting evil reign supreme in their lives. This is what is meant by “inward looking.”

Women and girls with disabilities craving for social transformation must borrow a leaf from the legacy of Steve Biko. The remaining question is how prepared are we to sail in such a turbulent sea?

Although it is ironic that women with disabilities, who by all parameters are the poorest of the poorest, are not categorically included in the SDGs, these goals, complemented by other instruments and interventions such as the CRPD, the CBR Guidelines and like, are the very boat to take us to the future, where we can live to our full potential in a society so inclusive that it leaves no one behind. Women with disabilities must demand for equity treatment in order to compensate for the time spent in seclusion.

Let us push ourselves into the centre of the new epoch-making process.

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CHAPTER 9

The Complementary yet Diverse Roles of Government and NGOs in CBR

Siame Musonda, Jose Diquissone Tole**, Miir Michael****

Summary

In order to achieve a more inclusive society in development, people with disabilities' concerns and experiences should be an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres of the Local Government. This can only be brought to life with effective networking, collaboration and ensuring the mainstreaming of disability issues at all levels of government. This not only facilitates effective utilization and allocation of resources but also enhances capacity for sustainability of programmes and services.

Introduction

In this chapter, the authors attempt to show how select governments and non-governmental organizations (NGOs) complement each other in delivering positive outcomes in CBR. They do this by synthesizing various papers and presentations at the 5th CBR Africa Network Conference that demonstrate how Community Based Rehabilitation (CBR) is initiated, the rationale that drives this initiative and what guides the processes. They also discuss the various roles played by the two parties in advocacy for disability inclusion in global goals, policy, guidelines and service delivery.

Community-based rehabilitation (CBR) was first initiated by the World Health Organization (WHO) following the International Conference on Primary Health Care in 1978, resulting in the Declaration of Alma-Ata. It was perceived as a strategy to improve access to rehabilitation services for people with disabilities in developing countries. Over the past 30 years its scope has considerably broadened and today, CBR has been embraced by many countries of the world.

In 2003, an International Consultation to review community-based rehabilitation held in Helsinki made a number of key recommendations. Subsequently, CBR was repositioned, in a joint International Labour Organization (ILO)/United Nations Educational, Scientific and Cultural Organization (UNESCO)/WHO paper, as ‘a strategy within general community development for the rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities’. In 2005, the World Health Assembly adopted a resolution on disability prevention and rehabilitation, urging Member States ‘to promote and strengthen community-based rehabilitation programmes’. CBR is currently implemented in over 90 countries.

CBR is usually started by a stimulus from outside the community, for example by a government ministry or NGO. Whether the interest originates from inside or outside the community, it is important to ensure that resources are available and the community is ready to develop and implement the programme. It is neither expected nor possible for the ministry, department, local authority or organization that initiates a CBR programme to implement every component of the CBR matrix. It is essential that they develop partnerships with different stakeholders responsible for each component of the matrix to develop a comprehensive programme. Each sector should be encouraged to take responsibility for ensuring that its programmes and services are inclusive and respond to the needs of persons with disabilities, their families and communities. For example, it is suggested that the ministry of health and/or NGOs working in the health sector take responsibility for the health component, the ministry of education and/or NGOs working in the education sector take responsibility for the education component, and so on.

CBR programmes are usually started with good intentions, but these are never enough to run and sustain the programmes. Experience has shown that government-led programmes or government-supported programmes provide more resources and have a larger reach and better sustainability, compared with civil society programmes. However, programmes led by civil society usually make CBR more appropriate, make it work in difficult situations, and ensure better community participation and sense of ownership. CBR has been most successful where there is government support and where it is sensitive to local factors, such as culture, finances, human resources and support from stakeholders, including local authorities and disabled people’s organizations.

It is recognised that NGOs have played a significant role in the development of rehabilitation services for persons with disabilities worldwide. This has been done usually in the absence of government involvement. In the past, NGO interventions took an institutional and charity approach. Currently, they favour a participatory, community-based strategy, complementing and liaising with government and working with all the stakeholders. NGOs and governments vary in their capacity to change their working practices to achieve their respective aims.

Complimentary and Diverse

One dictionary defines ‘complementary’ as ‘mutually supplying each other’s lack’ (Merriam Webster). It completes or enhances the qualities of something else. Other words that can be used are; corresponding, matching, and equivalent. The synonyms of ‘diverse’ include ‘different, dissimilar, unlike, assorted, distinct, and multifarious.’ Essentially this could mean that whilst the different parties are doing actions geared towards the same goal, these actions may be seen as corresponding, assorted, distinct and peculiar to the entity. This is how the roles of government and civil society are viewed in the delivery of CBR.

The role of Local Government(s) in CBR

- Formulating policy, review and promotion
- Establishing appropriate administrative structures
- Mobilising resources
- Decentralising to encourage community participation
- Training and sensitizing
- Establishing and maintaining referral options
- Monitoring and evaluation
- Coordinating of Government, NGO and private sector players

Examples of Local Governments Practising CBR

Many governments have adopted CBR as a strategy to deliver rehabilitation services to persons with disabilities. A few examples in sub Saharan Africa are Kenya, Uganda, Malawi, Zambia and Namibia.

Ministry of Local Government – Uganda

In 1991 the Government of Uganda (GOU) adopted CBR as the main strategy for delivery of rehabilitation services and ensuring full participation in poverty eradication programmes. The overall goal was to achieve full inclusion of persons with disabilities in the mainstream of society. In 1992, the programme was first piloted in 3 districts. In this pilot, ministries of Health (MOH), Education and Sports (MOES) and Gender, Labour and Social Development (MGLSD) together with the National Union of Disabled Persons of Uganda (NUDIPU) led the programme. However, the Ministry of Local Government has embraced CBR in the Sub County and District work plans and budgets after drawing on good practices from Tororo and Busia Districts. In doing so, CBR in Uganda demonstrates the multi-sectoral approach. When Uganda adopted the UN Convention on the Rights of Persons with Disabilities (UNCRPD), it maintained CBR as the main practical strategy for realizing the provisions in the Convention. All CBR activities are designed to meet the basic needs of persons with disabilities, reduce poverty, and enable access to health, education, livelihood and social opportunities while empowering persons with disabilities. All these activities fulfill the aims of the Convention thus ensuring that persons with disabilities enjoy human rights on an equal basis with others.

Role of NGOs/Civil society

The roles and responsibilities of civil society organizations (CSOs) and groups will vary depending on their level of operation; whether international, national, regional or community. Their roles and responsibilities will also be influenced by their level of experience and involvement in disability and CBR. Historically, many NGOs have been at the centre of CBR work, so they may be the driving force behind any new or existing CBR programme. Even Government led CBR programmes are or were supported by international NGOs.

Roles and responsibilities of NGOs in CBR:

- Developing and implementing CBR programmes where there is limited government support
- Providing technical assistance, resources and training for CBR programmes
- Supporting the development of referral networks between stakeholders
- Supporting CBR programmes to build the capacity of other stakeholders
- Promoting mainstreaming of disability into existing programmes and services

- Supporting the evaluation, research and development of CBR
- Demonstrating to government the possibilities provided by CBR so that government adopts the concept

Examples of Civil Society Groups Practising CBR

Mobility India

Mobility India is a non-governmental organization based in Bangalore, India. It has been promoting CBR since 1999, with the goal of achieving an inclusive society where people with disabilities have equal rights and good quality of life. It carries out CBR programmes in three different locations; in urban slums, peri-urban and rural areas. While the programmes in each of these areas implement common activities such as facilitating the formation of self-help groups, facilitating access to health, education, livelihood and social opportunities, and community mobilization, they also display unique differences because of the different contexts in which they operate.

CREATE (CBR Education and Training for Empowerment)

CREATE is a non-governmental organization based in KwaZulu Natal province in South Africa. Its focus is on advocacy for disability rights and community based rehabilitation in its broadest sense. It works with disabled people's organisations, parents' groups, communities, municipalities and government departments as well as other NGOs and businesses. Its expertise is in training and advocacy work and its advocacy and lobbying activities take place at local, provincial, national and international levels.

OREBACOM in Mozambique (Organização de Reabilitação Baseada na Comunidade em Moçambique- Community Based Rehabilitation Organization in Mozambique)

In Mozambique, schools did not accept children with intellectual disabilities and if they did, the children received little attention. OREBACOM started teaching children with intellectual disabilities in their office. They successfully lobbied the local government to support their initiative. OREBACOM also has children's sports and games group which meets once a week. The CBR workers bring the children to the sports and games.

CBR Guidelines and UNCRPD: How do These Influence Policy?

CBR Guidelines

The development of the CBR guidelines was strongly influenced by the Convention on the Rights of Persons with Disabilities (CRPD). The CBR Guidelines are a strategy which can contribute to implementation of the Convention on the Rights of Persons with Disabilities. The Convention on the other hand facilitates development of disability inclusive legislations which contribute to community-based inclusive development. The Convention and subsequent national policies and laws provide practical suggestions on how to develop or strengthen CBR programmes that ensure access to health, education, livelihood and social sectors.

In addition, the CBR Guidelines provide a common understanding and approach to inclusion of persons with disabilities. The CBR Matrix presents an overall visual representation of CBR. The Matrix illustrates the different sectors, which make a CBR programme. The Matrix consists of five components, each with five elements. The components and elements are underpinned by principles which inform implementation.

Implementing CBR is a 'pick and mix' series of options; a set of components and elements from which the practitioner can select depending on local needs resources and mandate. The Matrix should not be seen as sequential. At the same time, the implementer needs to be in touch with other key organizations that address other components and elements. Effective actualization of the CBR Matrix requires development of strong networks, collaboration and information sharing.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The Convention, which was signed in March 2007, became international law on 3 May 2008. The Convention re-affirms existing human rights declarations in the context of disability and focuses strongly on the discrimination experienced by persons with disabilities worldwide. Countries that sign and ratify the convention are obliged to implement it at the national level.

The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

The principles of the Convention are:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;

Many CBR programmes design their activities around the CBR Guidelines (using the CBR Matrix) and the principles espoused in the convention. CBR is also perceived as a strategy for realization of the Convention.

Including Disability in Global Development Goals

In September 2000, UN Member States adopted eight Millennium Development Goals (MDGs), which ranged from eradicating extreme poverty and hunger to providing universal primary education, all by the target date of 2015. These internationally agreed development goals represented the benchmarks set for development at the start of the new century. While the MDGs did not explicitly mention disability, each goal had fundamental links to disability and could not be fully achieved without taking disability issues into account. Therefore in November 2009, the Sixty-fourth UN General Assembly adopted a resolution on 'Realizing the Millennium Development Goals for persons with disabilities' (A/RES/64/131). In September 2010, Resolution (A/RES/64/299), was adopted, 'Keeping the promise: united to achieve the Millennium Development Goals', in recognition that policies and actions must also focus on persons with disabilities so that they too benefit and progress towards achieving MDGs.

'Beyond 2015' is a global civil society campaign, pushing for a strong and legitimate successor framework to the Millennium Development Goals. The campaign, created in 2010, is built on a diverse, global base. It ranges from small community based organisations to international NGOs, academic and trade unions. A founding principle of the campaign is that it is a partnership between

civil society organisations from the 'North' and the 'South' – bringing together groups from developing, emerging and developed economies.

As a result of concerted effort by 'Beyond 2015', the Global Agenda 2030 has adopted the slogan 'leaving no one behind'. The Sustainable Development Goals therefore provide for marginalized sections of society to benefit from development interventions. For example, five of the targets specifically address disability and all targets that measure equalization inevitably include disability.

Collaboration/Networking in CBR

The goal of CBR is; inclusion, empowerment and improved living conditions of persons with disabilities. It aims at facilitating an independent life style where persons with disabilities participate in all aspects of community life on an equal basis with others. Multi-sectoral collaboration and networking is crucial if such a goal is to be achieved. The partnership should be between the various sectors including health, education, labour, vocational, housing, welfare, sports and agriculture in collaboration with NGOs, Disabled Persons' Organisations (DPOs) and the traditional and religious institutions.

Despite the importance of partnerships and networks in CBR, an integrated response has not been achieved for various reasons including:

- Lack of political will reflected in the absence of a national policy on disability issues or CBR.
- Poor communication between government ministries and amongst different stakeholders
- Competition between sectors, each wants to be perceived as the 'lead' agency and compete for the sphere of influence.

A policy that clearly spells out the lead sector at national and sub-national level will improve collaboration especially if the lead agency is facilitated with basic provisions to host collaborative committees and meetings, at which resources are mapped and interventions jointly planned.

Conclusion

Whether the interest originates from inside or outside the community, it is important to ensure that resources are available and the community is ready to develop and implement the CBR approach. It is neither expected nor possible for the Ministry, local authority or organization that initiates a CBR programme to

implement every component of the CBR Matrix. It is essential that they develop partnerships with the different stakeholders responsible for each component of the Matrix, in order to develop a comprehensive programme. Multi-sectoral collaboration and networking is crucial and could be fostered through creation of CBR Networks or Coordinating Committees.

Recommendations

- Governments interested in advancing disability issues and the CBR approach should develop a CBR Policy alongside or within the Disability Policy.
- Establishment of a Coordinating Committee, National CBR Networks or Associations should be encouraged as this will ensure multi-sectoral collaboration, good coordination and efficient delivery of services to persons with disabilities; an aspiration of CBR.

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CHAPTER 10

ICT to Promote Accessibility for Persons with Disabilities

*Maholo Carolyne Sserunkuma**

Summary

Access to information is one of the barriers to communication for persons with disabilities. It requires both individual capacity in accessing the information and appropriate provisions with Braille, sign language, tactile communication, ICT and use of information charts.

The introduction of Information and Communication Technology (ICT) and Assistive Technology (AT) have greatly enhanced participation of persons with disabilities. ICT is instrumental in education of persons with disabilities; however, the twin-track approach should be adopted for better results.

Introduction

About 15% of an average population is reported to be persons with disabilities, according to the World Report on Disability (WHO, 2011). Ten percent (10%) of the world's children and young people (approximately 200 million), have sensory, intellectual or physical impairment (WHO, 2000).

The International Classification of Functioning, Disability and Health (ICF), defines disability as an “umbrella term for impairments, activity limitations or participation restrictions”, which result from the interaction between the person with a health condition, environmental factors (e.g. the physical environment, attitudes), and personal factors (WHO 2001). The UN Convention on the Rights of Persons with Disabilities (2006) defines persons with disability as “those who have 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”.

Persons with disabilities experience communication barriers, attitudinal barriers, architectural barriers and environmental barriers. Information and

communication technology (ICT) and Assistive Technology (AT) are perfect solutions for mitigation of such barriers. In this era, ICT is a basic requirement for participation of persons with disabilities since they can hardly manage life without assistive technology. Their adoption and use requires use of the twin-track approach in which individuals are prepared with appropriate knowledge and skills while the system or environment is prepared as well. This approach is aimed at empowering and enabling accessibility for effective inclusion; by the time persons with disabilities are ready to engage in activities, the environment is ready to receive them. It is attributed to the notion that:

“It takes two to tango.”

Neither provision of the technology nor competence in utilizing it works in isolation. Technology is only useful to people who know how to manipulate it. Without the two in combination, persons with disabilities remain excluded.

Agony of Exclusion!!!!

Can you imagine a life without communication?

Where you rely on others to know what happens around you!

In this era of HIV and other deadly illnesses, you cannot access information! What about a life where you bump into things and each time you do, all people laugh and call you names.

No one wants anything to do with you since they are afraid of contamination. That is a life that two blind boys (Byarugaba and Barugahare) experienced in one of the popular integrated school in Eastern Uganda. Byarugaba dropped out along the way. His reasons for dropping out will never be known. Without knowledge and information on disability, people share myths that worsen exclusion. Many people are unaware of the fact that disability is not contagious and as a result, they exclude them.

A Blind Girl in a Rural Community

Eight year old Nyaburu was constantly insulted. She always felt too low to even look into anyone's eyes. Her mother and siblings often insulted her for bumping into things while she walked. She was dirty and full of jiggers. When a community based rehabilitation intern student recommended school for Nyaburu, her mother exclaimed; "That one who cannot even pick vegetables. How can that one go to school?" They all burst into laughter. Nyaburu looked down and shed a tear.

The little girl had low vision and loved school but because of inability to walk straight without bumping into things, occasionally staggering and falling, failure to pick vegetables or sort the millet grains, she was declared incompetent. The insisting student brought a ray of hope in Nyaburu's life by referring and insisting on her going to school.

Despite the lack of trained personnel and the appropriate educational material in the neighborhood school she attended, Nyaburu realized a great improvement in esteem and learnt to keep clean just like any other school going child.

For several years, Nyaburu relied on her memory to follow the teaching in class but her good academic performance earned her popularity and she later got a sponsor to help her through school.

With ICT, people like Nyaburu can access quality education to join the productive sector of the economy in contribution to attainment of the Sustainable Development Goals. Persons with disabilities have a right to decent work as declared in Sustainable Development Goal number eight (8) (UN 2015) and ICT is the best tool to its realization.

People with hearing impairment are locked up in a world of their own. Imagine a world where people speak a language you do not perceive! Each time they laugh you wonder what is happening. Anxiety and tension increase and that is how you live until the door is opened to let you into their "world". People with hearing impairment have no means to inform others about what they know, feel or want. Without sharing information, they burn with anxiety and speculation.

Despite the proclamation of universal primary education many children with disabilities drop out of school. The highest rate of drop-out has been reported among children with movement challenges and those with epilepsy.

Many schools have inaccessible steep/narrow entrances. They also lack modified toilet facilities with squatting rails or frames which are required for accessibility especially by persons with movement challenges.

“Having a wheel chair eases mobility but what about the toilet. Can you imagine sweeping your uniform through the filth in the toilet? And each time you come to class they all run away due to the bad smell. Sometimes I would go to school without food to avoid using the toilet.” School drop-out in Mbarara, Western Uganda.

Children with epilepsy have always been victims of the myths about epilepsy. Like many of us, people believe that epilepsy is contagious and as a result, children with epilepsy are left without assistance. They later suffer the humiliation and exclusion, with other children afraid of catching the “disease”.

How many more persons with disabilities endure these and more forms of exclusion? We all have to attain the 2030 goals: *“Leave no one behind”*.

Policies on Accessibility

Several policies have been developed to promote inclusion of persons with disabilities earlier. However, the 1993 UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities addressed the various challenges they experience. The Standard Rules specifically highlighted preconditions for equalization, target areas for equalization and implementation measures to facilitate effective inclusion. UN Standard Rule number five (5) was specifically on accessibility (UN 1993). In 1994, inclusive education was declared at Salamanca (UNESCO 1994). This was based on an observation that persons with disabilities were missing out in education.

In 2000, the Millennium Development Goals were declared. Despite their intention to enhance the lives of all people, disability was not given much emphasis and as a result, persons with disabilities remained excluded throughout their implementation. In 2006, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) came into existence. It stipulates the need for all persons with disabilities of various categories to access information on all aspects of life. It also emphasizes elimination of all kinds of barriers to promote equal

participation. The UNCRPD encourages innovation, science and technology to facilitate growth and development of ICT to meet the varying needs of persons with disabilities. ICT facilitates access to education, information and other facilities that widen opportunities for persons with disabilities.

In the Kenya Constitution (GoK, 2010): Bill of Rights Chapter 4, Article 43 (f), Education is a basic human right that every Kenyan must be accorded. Article 27 guarantees equality and freedom from discrimination for all Kenyans, while Article 54 clearly states the rights and privileges of persons with disabilities derived from the Constitution.

The Kenya Persons with Disabilities Act (2004) stipulates and mandates observation of rights, privileges and protection of persons with disabilities, and ensuring their full access to education and training programmes. This is aimed at facilitating inclusive development.

In African countries, appropriate policy formulation, implementation, monitoring and capacity development in various fields to ensure accessibility will greatly facilitate inclusion of persons with disabilities. With advancement of technology, ICT and assistive technology are a key to inclusion.

Government's Effort to Promote Inclusion in Uganda

Uganda has adopted many international policies. The 1995 Constitution of Uganda prohibits discrimination of all people including persons with disabilities. The Constitution also recognizes the need for accessibility including access to information and justice. As a result, sign language provisions are mandatory in public communication to ensure that persons with hearing impairment are not excluded.

In 1996 and 1997, the Parliamentary Elections Statute and Local Government Act came into existence respectively. With these, persons with disabilities have a slot in which they are expected to adequately advocate for their cause. However, not much has been attained in ensuring inclusion of the poor vulnerable persons with disabilities who are still excluded.

In 1997, Universal Primary Education was declared. It was adopted from inclusive education declared at Salamanca although it was politicized from inception and has not received much popularity. The Local Government act was

aimed at ensuring effective representation of persons with disabilities at different local councils. Despite the coincidence, inclusive education still faces difficulties and many persons with disabilities are still locked out of school, a situation that deprives them a chance to access, utilize and benefit from ICT.

In 1998, the Movement Act came to increase representation of persons with disabilities in the public sphere. Uganda is currently one of the countries with the highest rate of representation of persons with disabilities in the public sphere. In the same year, the Road Traffic Act was passed to prohibit denial of driving permits to persons with disabilities. This was done with recognition of the ICT and assistive technological advancement to promote inclusion. The Act also encourages research to enhance ICT and technological advancement. In the same year (1998), the Communications Act was passed to promote research in the development of ICT and assistive technology.

In 2003, the National Council for Disability Act came into existence. The Council is expected to monitor observation of the rights of persons with disabilities as set out in international conventions, legal instruments and the national policies.

In 2006, the Persons with Disabilities Act was passed to ensure elimination of all forms of discrimination against persons with disabilities and ensure inclusion. It stipulates 15% tax exemption to employers who hire ten or more persons with disabilities as regular employees, apprentices or learners on full time basis. This increases chances for persons with disabilities to access employment although it has not yet realized much result. In the same year, the National Disability Policy, the Equal Opportunity Act and Employment Act were passed to ensure equal access to employment opportunities.

In 2008, the Business, Technical, Vocational Education and Training (BTVET) Act was declared to promote equitable access to education and training for all disadvantaged categories of people including persons with disabilities.

All these policies are aimed at promoting inclusion of persons with disabilities in all aspects of life. However, without ICT and assistive technology none of these can be actualized. In Uganda, government has worked with partners to provide computers and other assistive technology to schools especially to serve the learners with visual impairment at different levels of education. However, this effort is frustrated with limited capacity to effectively embrace the technology needed for inclusion. Much as ICT is being promoted across the globe, it should

be backed up by appropriate capacity development for empowerment of the persons with disabilities, to make inclusion a reality.

The Role of ICT and Assistive Technology



A person with low vision using a computer in Kenyatta University, Nairobi, Kenya

Innovation, science and technology facilitate growth and development of ICT to meet the varying needs of persons with disabilities. ICT and assistive technology are vital in promoting education among persons with disabilities to enhance their capacity and widen their opportunities.

With ICT, persons with visual impairment are able to research and benefit from the multitude of information on the internet.

In developing countries where 80% of persons with disabilities are poor and illiterate, many cannot afford ICT and assistive technology. With the popularity of mobile telephones, some persons with disabilities are accessing the little ICT available since many phones have internet facilities and various modifications to suit the long excluded persons with visual impairment.

Majority of persons with disabilities need and benefit from assistive technology such as mobility equipment like wheel chairs, hearing aids and special seats among others. Advancement in technology has brought on the market motorized mobility technology, a fast means of mobility for people with movement challenges and other technology for persons with disabilities. However, mobility devices can only be utilized in a modified environment. There is therefore need for provision of ramps, wide doors and corridors, accessible toilets with seats, rails or frames which provide support to ease toilet use among other required infrastructure.

Other assistive technology includes hardware and software that enable access to a computer such as adaptive keyboards and screen readers. Default settings on computers can be adjusted depending on individual needs. There are alternative pointing or input devices, such as a roller ball or switch for people who are unable

to access a keyboard using their hands or arms but have a good head, neck and upper torso control. They use these using a mouthstick or head/chin point.

ICT is particularly vital in promoting accessibility to information by persons with visual impairment and sometimes persons with hearing impairment. For these two categories, emergency exits should be made accessible with auditory and visual alarm systems, evacuation policies and evacuation chairs so that they easily escape danger in case of disasters. This should preferably be accompanied with appropriate training so that they are able to utilize the provisions.

According to UNESCO (2010), identifying best assistive technology solution requires in-depth needs assessment to understand how impairment impacts computer use and/or access to an educational resource by students with disabilities.

ICT for Sustainable Development

The recently concluded Millennium Development Goals did not give much emphasis to disability. However, the commendable effort by various disability advocates facilitated development of the more inclusive SDGs with a slogan; *“Leave no one behind”*. Attainment of these goals requires elimination of barriers to participation of persons with disabilities. Elimination of extreme poverty and hunger, attainment of universal health, universal education, universal access to modern energy services and all other SDGs cannot be attained by all without ICT and assistive technology.

Continuous use of printed materials, videotapes, televised presentations, overhead transparencies and other visual materials create accessibility challenges to persons with visual impairment. However, this can be mitigated with alternative media such as use of audiotapes, provision of Braille material, electronic text, tactile drawings and aural descriptions among other modifications.

Education, health and poverty are mutually related. Poverty is a key determinant of health and education, and yet health determines effective education, which in turn facilitates livelihood and hence poverty reduction.

Inclusive Education was declared in 1994. Since then, many other policies have been developed to promote education for all and yet many persons with disabilities especially those with visual impairment and hearing impairment are still excluded. According to UNESCO, 90% of children with disabilities

from low income countries do not go to school (UNESCO, 2014). Exclusion is largely attributed to ignorance of disability, the needs of the various persons with disabilities, their rights and the need for them to actively engage in everything that concerns them, their families and communities. Considering the 15% rate of disability, exclusion of persons with disability has a great impact of countries' GDP and development. Many economies of Africa endure this loss, hence the urgent need for inclusive development.

ICT Provisions in Academic Institutions

In Uganda, Kyambogo University is known for capacity development in disability management. In the Faculty of Special Needs and Rehabilitation, various services and facilities exist to promote accessibility to education. In collaboration with some stakeholders in the disability fraternity, the Faculty has an equipped ICT Centre for students with visual impairment and another for persons with hearing impairment.

The ICT Center has well trained personnel with both ICT and rehabilitation skills. In the ICT Center, students are provided with basic skills to utilize Braille facilities and the various computer packages available.



Peer learning in the ICT center of Kyambogo University, Uganda (Photo courtesy Kyebagadda Binasali)

On arrival at the University, all new students are oriented with all assistive technology so that they maximize its use throughout their stay. The centre serves students from different Faculties in the University. Students access internet, utilize the adapted computers and have access to some transcribed material including text books. During examination time, papers are brought to the centre for appropriate transcription to enhance accessibility. They are also given an extra 30 minutes for each exam as affirmative action. Many of the students are empowered to embrace ICT for all their assignments and examinations in preparation for inclusion when they graduate.



Students try out the research skills acquired to prepare a course assignment at Kyambogo University, Uganda (Photo courtesy Kyebagadda Binasali)

Conclusion

Persons with disabilities are an important human resource that should be utilized to promote inclusive development. ICT and assistive technology are instrumental facilities for disability inclusion. It however requires collaboration and networking to ensure empowerment of persons with disabilities, along with appropriate provisions and facilitations to ensure accessibility. Attainment of the Sustainable Development Goals will only be realized when all people take part in the development process.

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Resolutions of the 5th CAN Conference held at KICC, Nairobi-Kenya, 1-5th June 2015

1. All CBR stakeholders should recognize and promote the active participation, involvement and ownership of all phases of CBR programmes by Disabled Peoples' Organizations (DPOs) as well as family-based organizations of persons with disabilities.
2. Leveraging/networking: There is need to work closely with established organizations and institutions to mainstream disability at all levels.
3. Data on disability: All CBR practitioners need to collaborate with line government institutions to ensure use of available data to inform CBR programming and at the same time explore opportunities for generating new data.
4. Advocacy on CBR: All CBR practitioners, and organizations of persons with disabilities and their families should advocate for governments to ensure effective harmonization of policy and practice.
5. CBR and Microfinance: CBR programmes will remain focused and engaged in ensuring savings and loans schemes include persons with disabilities.
6. Governments should take leadership on disability inclusion through line ministries as well as ensure adequate allocation of resources.
7. Information sharing on CBR: There should be enhanced communication on CBR activities to promote learning and exchange of good practices. CBR networks should be established and strengthened at national, regional and global levels.
8. Participation of both women and men with disabilities: Governmental and non-governmental organisations should ensure participation of both women and men with disabilities at all levels of decision making, planning, policy development, monitoring and evaluation.
9. CAN should continue to disseminate, support and promote knowledge and information exchange across the CBR network.
10. Shift from Community Based Rehabilitation (CBR) to Community Based Inclusion (CBI): Recommend for further discussion at the global CBR

Conference but with Africa Position as CBI; with gradual change and sensitivity to the grass-root (the meeting is recommending that this is proposed to the global network).

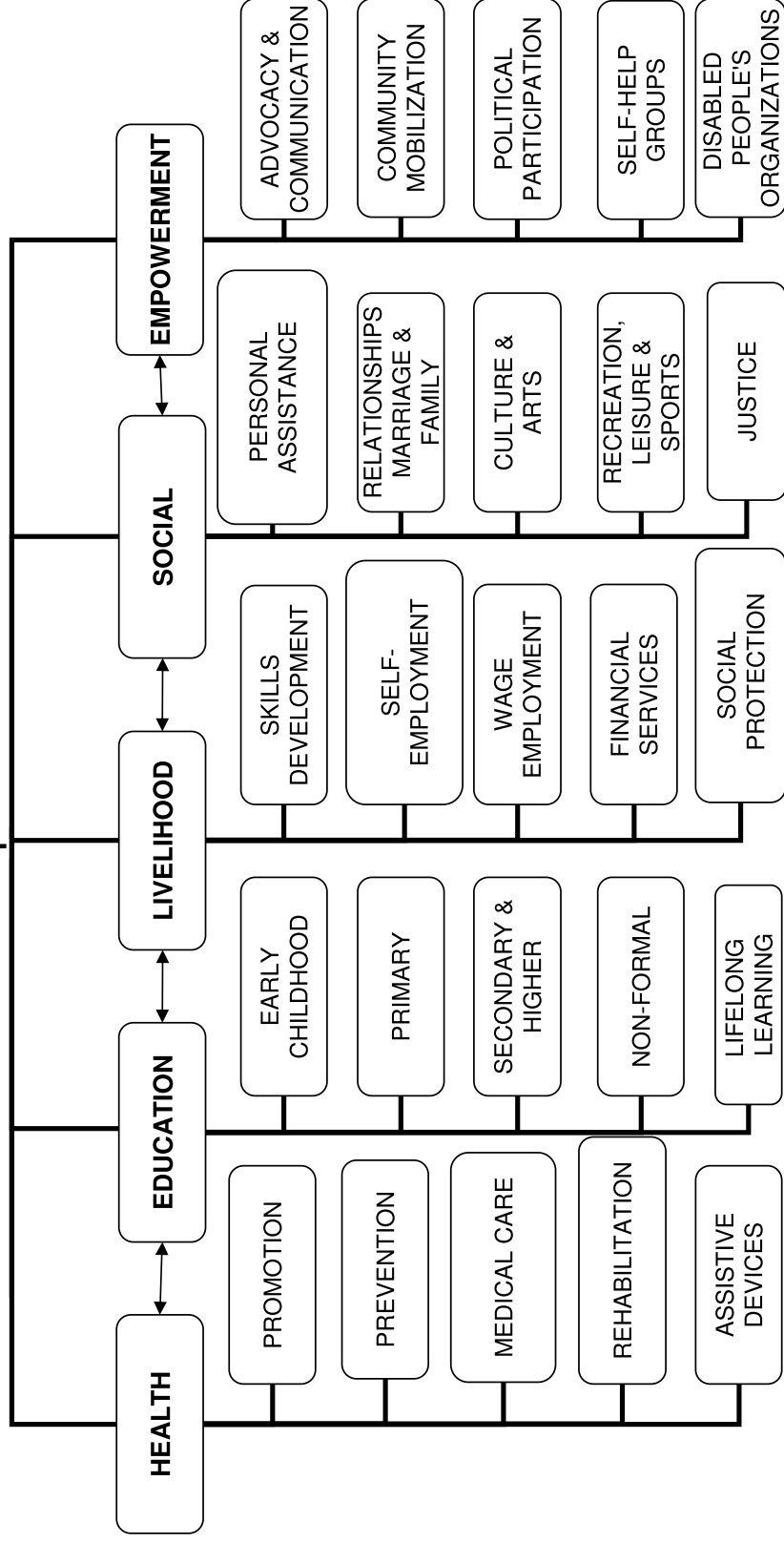
11. Bring CBR community participation into regular schools in order to base teaching on the reality of the learners, reach a better quality education and create the conditions for inclusion.
12. Ensure increased participation of the deaf and of women with disabilities at the next CAN conference.

APPENDIX 1

CBR Africa Network (CAN) Conferences

1. “Community-based Rehabilitation (CBR) as a Participatory Strategy in Africa”, September 2001, Kampala, Uganda.
2. “CBR as Part of Community Development – A Poverty Reduction Strategy”, August 2004, Lilongwe, Malawi.
3. “CBR: Inclusive Policy Development and Implementation” October 2007, Johannesburg, South Africa.
4. “Linking CBR, Disability and Rehabilitation”, October 2010, Abuja, Nigeria.
5. “CBR Guidelines: A Bridge to Inclusive Society Beyond the 2015 Development Framework”, June 2015, Nairobi, Kenya.

CBR MATRIX





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