# Summary Report of the 6th CBR Africa Conference

Intercontinental Hotel Lusaka, Zambia 7-11 May 2018







#### Theme:

CBR for resilience building and sustainable development: Leave no one behind



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# Glossary

**AfriNEAD** The African Network for Evidence to Action in Disability

AIDS Acquired Immune Deficiency Syndrome

**CAN** Community Based Rehabilitation Africa Network

**CBID** Community Based Inclusive Development

**CBM** Christoffel Blindenmission

**CBO** Community Based Organization

**CBR** Community Based Rehabilitation

**CoRSU** Comprehensive Rehabilitation Services in Uganda

**CPD** Continuing Professional Development

**CRPD** United Nations Convention on the Rights of Persons with Disabilities

**CSO** Civil Society Organization

**DiDRR** Disability Inclusive Disaster Risk Reduction **DMIS** Disability Management Information System

**DPI** Disabled People International

**DPO** Disabled People's Organization

**EC** Executive Committee

**ECD** Early Childhood Development

**FEDOMA** Federation of Disability Organizations of Malawi

**FPP** Focal Point Person

**GATE** Global Cooperation on Assistive Technology

**HI** Humanity and Inclusion

**HEfDA** Harmee Education for Development Association

**HIV** Human Immunodeficiency Virus

IE Inclusive Education

ICACBR International Centre for the Advancement of CBR



**JICA** Japan International Cooperation Agency

**LF** Lymphatic Filariasis

MACOHA Malawi Council of the Handicapped

**MCDSS** Ministry of Community Development and Social Services

MHUNZA Mental Health Users Network of Zambia

**NAD** Norwegian Association of Disabled

**NCPWD** National Council for Persons with Disabilities in Kenya

**NGO** Non-governmental Organization

**OPD** Organization of People with Disabilities

**PSGs** Parent Support Groups

**RBA** Rights-Based Approach

**SAFOD** Southern Africa Federation of the Disabled **SDGs** Sustainable Development Goals

**SEEPD** Socio Economic Empowerment of Persons with Disabilities

**TLM** The Leprosy Mission

**ToT** Training of Trainers

**UNICEF** United Nations Children's Fund

**VCBRA** Vision Community Based Rehabilitation Association

**VSLA** Village Savings and Loan Association

**WHO** World Health Organization

**ZAFOD** Zambia Federation of Disability Organizations

#### Acknowledgments

We would like to take this opportunity to thank CAN's donors (Norwegian Association of Disabled and CP Charitable Trust) and conference sponsors (Government of the Republic of Zambia, Liliane Foundation, Light for the World, CBM and Humanity and Inclusion) for their contributions towards the 6th CBR Africa Conference and for their ongoing support of CAN, without which our work and events would not be possible.



For more information on CAN and for access to the full presentations given at the CBR Africa Conference please see our website at: <u>http://www.afri-can.org</u> or contact us at: <u>info@afri-can.org</u>

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### Foreword

I am proud that the 6th CBR Africa Conference was successfully held in my home country Zambia from 7-11 May 2018 under the Theme: **CBR for resilience building and sustainable development: Leave no one behind.** 

On behalf of CBR Africa Network (CAN), I cannot express the delight and appreciation that His Excellency Mr. Edgar Chagwa Lungu, President of Zambia, and the First Lady, Madame Esther Lungu, graced the conference as guests of honour. They both gave inspiring speeches on inclusive development, highlighting the challenges experienced by people with disabilities in Zambia and the world today. This was inspiring not only for Zambia but also for Africa as a whole. Their presence and commitments highlighted the relevance of Community Based Inclusive Development (CBID) as a strategy to ensure fulfilment of the sustainable development goals *"leave no one behind"*. It is also evident from the many presentations and comments from delegates that the shift from CBR to CBID has started and it must be sustained.

The 6th CAN Conference brought together 542 participants from 38 countries, who once again shared their expertise and learning through presentations, workshops and general networking.

CAN conferences are the climax of the CAN calendar and provide a unique opportunity for CBR/ CBID stakeholders to share information and generate lessons, debate issues and help the sector to move forward in a common direction.

This conference also marked the completion of my first three-year term as Chairperson of CAN and I am honoured to be given an opportunity to serve a second term and lead CAN forward until the 7th CBR Africa Conference in 2022.

My heartfelt appreciation goes to all of CAN's Executive Committee members, donors, partners, and supporters, the dynamic conference organizing committee members and all other stakeholders who played their parts in making the conference a success.



Musonda Siame - Zambia CAN Chairperson musonda@afri-can.org

# CBR Africa Network (CAN)

CAN was founded in 2001 and exists to promote appropriate access to information on disability and development for all people in Africa. CAN works closely with disabled people's organizations, government agencies, disability organizations, development organizations, and national and regional decision makers to create increased awareness of, and support of CBID as an effective approach to realizing the UN Convention on the Rights of Persons with disabilities (CRPD) and the Sustainable Development Goals (SDGs). CAN is also the African regional affiliate of the CBR Global Network.

CBR Africa conferences are held every 3-4 years to bring together in one place the spectrum of CBR/CBID stakeholders from across the continent and internationally to share information, their learning and expertise, and to renew old alliances and forge new ones.

This was the 6th CBR Conference, following the 5th CBR Conference held in Nairobi in 2015, and previous conferences in Nigeria, South Africa, Malawi, and Uganda. No conference is without its challenges, and the 6th CBR Africa Conference was no exception! Among these challenges was the change in location of the conference from Livingstone to Lusaka. However, government of Zambia worked with us to overcome many of these challenges. The Zambian government generously supported the conference and graced it by officiating it with the presence of the President and First Lady of Zambia. I am delighted to say that the conference was a great success.

As always, the programme included the CAN AGM and elections of a new Executive Committee. The new CAN Executive committee is made up of members from Cameroon, Egypt, Kenya, Nigeria, Togo, Uganda and Zambia. The AGM also approved amendments to the CAN Constitution.

After each conference we produce a CAN Book, which includes collaborative chapters by presenters of papers at the event. However, we have also introduced this Summary Report in an effort to share learning and knowledge from the conference in advance of the book's publication. We very much hope that whether you were able to attend the conference or not, you will enjoy this publication and continue to contribute to CAN through our events, website, and social media platforms.



Abdul Busuulwa CAN Executive Director abdul@afri-can.org

# Chair of the conference planning committee

I was honoured to be appointed by the Secretary to the Cabinet as the Chair of the 6th CBR Africa Conference, with a committee that included senior government officials from line Ministries, DPO's, Civil society and Academia. The highlight of my role and that of the committee was the confirmation that the President of Zambia, His Excellency Mr. Edgar Chagwa Lungu and the First Lady, Madame Esther Lungu would attend the event. We are extremely grateful to the President and First Lady for demonstrating this important commitment to Community Based Inclusive Development (CBID) and the sharing of ideas and learning that each CBR Africa Conference provides.

We are proud to say that the government of Zambia also provided substantial financial and operational support to the conference, underlining their commitment to CBID in Zambia and their support of the networking and sharing that the CBR Africa Conferences provide.

Our organizing committee included 60 representatives from a diverse range of CBID stakeholders in Zambia, including more than 10 government ministries, NGOs, DPOs and service providers, divided into a range of committees with different responsibilities.

The conference programme was a rich one thanks to the work of our Technical Committee members and speakers from all corners of the African continent and beyond. Good practices were shared, as well as lessons learned in the implementation of CBID projects in all regions. The programme included Keynote speakers, parallel sessions and workshops, as well as field visits to different venues in Lusaka on the final day.

Our committee also included sub-committees of Publicity and Public relations, Hospitality and Security, Fundraising and Finance, and Programme and Technical. I would like to extend my sincere gratitude to each and every member of the organising committee for the tireless work that contributed to the event's success.

We are honored that CAN chose Zambia to host this important event in the CBID Calendar and we wish CAN every success as it moves forward with its plans for the next conference in 2022.



**Dr Liya Nawa Mutale** *Permanent Secretary* 

Ministry of Community Development and Social Services, Chairman of the 6th CBR Africa Conference Organizing Committee

# Opening ceremony and keynote speakers

The official opening ceremony of the 6th CBR Africa Conference was held on the second day of the conference due to the availability of His Excellency the President of the Republic of Zambia. The session began with the National Anthem and opening prayers. CAN's Chairperson, Musonda Siame, expressed CAN's gratitude to the President and the Government of Zambia for having accepted to co-host and commit resources to this 6th CBR Africa Conference. He noted that the commitment demonstrated what can be achieved through a well coordinated partnership between government and disability stakeholders in promoting inclusive development in accordance with Agenda 2030 and the CRPD. He also emphasized the role of CBR Africa Network (CAN) as an informationsharing network.

Musonda referred to the paradigm shift from CBR to CBID and noted that CAN had not wanted to leave the grassroots behind but that sufficient time had now passed and the shift has already taken root. He noted *"CBR for resilience building and sustainable development - leave no one behind", should not just be the theme for this 6th conference, it should translate into actions to enhance resilience for the attainment of the sustainable development goals. Let us all work together to facilitate the transition toward Community Based Inclusive Development (CBID)"*.

The Chairman of CAN listed the nine subthemes relevant to the current discourse that would be covered in the presentations and discussions to cover the diversity of issues that affect humanity and people with disabilities in particular. He said *"You will hear new insights into CBID"*. Musonda Siame acknowledged the significant support from the World Health Organisation (WHO), Christoffel Blindenmission (CBM), The Norwegian Association of Disabled (NAD), Light for the World, Humanity and Inclusion, and the Liliane Foundation for their technical and financial support directly and through delegate sponsorship. He also acknowledged the support of the CAN Executive Committee members, and the local Conference Organizing Committee and reported that the conference had attracted 542 delegates from 38 countries, including 30 African countries. Musonda Siame completed his address with some words from CAN's Patrons Chris Brewer of the CP Trust and CAN Founder Sally Hartley, who were unable to attend the conference.

Following this, the Mayor of Lusaka, Chisala Wilson Kalumba, welcomed delegates to Lusaka and expressed his optimism that the conference would provide opportunities to improve the lives of people with disabilities.

The group 'Zuba ni Moto' provided entertainment before the Minister of Community Development and Social Services (MCDSS), the Honourable Emerine Kabanshi, Member of Parliament, gave her remarks. The Minister noted that CBR is key in enhancing the quality of life of people with disabilities and their families and applauded the government for having prioritized the legal framework for disability. She also acknowledged the shift from CBR to CBID as a vehicle to align the SDGs and the Zambia 7th National Development Plan.

His Excellency the President of Zambia, Mr. Edgar Chagwa Lungu then shared his insights with the CBR Africa Conference delegates. An abridged version of his speech is given below.

We are deeply honoured that the 6th CBR Africa Conference is being hosted by Zambia. This is a manifestation of the confidence that the Community Based Rehabilitation African Network (CAN) have in the Republic of Zambia. We do not take this opportunity lightly because for us, this is the time and chance to raise the disability banner even higher for inclusive development.

Our hosting of this conference depicts the tremendous commitment that we attach to issues of disability. We have committed ourselves

to upholding democratic principles and good governance and this is to ensure that our values relating to family, morality, patriotism and justice are maintained and all functions of the state are performed in our common interest. This commitment also underscores the equal worth of children, women and men regardless of their disability and social status. We are therefore committed to strengthening inclusive development leaving no one behind. I am happy that we are hosting this conference in which we will share best practices across Africa, and around the world, on action research and documentation. For effective planning, monitoring and evaluation, as well as programme implementation, it is imperative to disaggregate data.

Our citizens here in Zambia and across Africa, are entitled to better lives. However, children with disabilities often face marginalisation within the family, at school, and within their community, leading to poor health and education outcomes. This affects their self-esteem and chances for participation and interaction with others is very low and increased risks to violence and abuse, including sexual exploitation. We need to do something about this.

In Zambia when people talk about their family members, they do this to the exclusion of their children with disabilities. We have also come across instances where people are divorced on account of their disabled children. I am therefore happy that one of the thematic areas for this conference is community based rehabilitation, gender and child protection. In this regard, I wish to encourage delegates to this conference to deliberate on effective ways of enhancing the lives of children with disabilities. In Zambia, we do not want to hear of children being hidden in communities. We want inclusive development for everyone. This can only happen if we change the mindsets of our people. Addressing the well being of people with disabilities is a priority. This is why I am here today, to showcase the importance my government attaches to matters of disability in Zambia.

Excluding people with disabilities from national development is retrogressive because the effects of this practice do not only affect the individual, but also the entire nation. This can lead to productivity loss and indeed human loss. The onus is therefore on all of us to promote sustainable and resilient societies across the globe. When this is done, everyone, especially people with disabilities will be given an opportunity to reach their full potential in both public and private sectors. We should always remember that disability is not synonymous with inability.

I call upon everyone present here today, to ensure that we mainstream issues of disability in our policies for us to achieve the Sustainable Development Goals and even beyond. There is need to ensure that our structures include facilities such as ramps to facilitate the free movement of people with disabilities. Time has come for us to change the way we look at people living with disabilities. Our engineers and planners must revisit their planning, and policy makers must take into account disability issues.

Let me now take this opportunity to wish all international delegates a warm stay in Zambia and encourage you to visit our tourist attractions around Lusaka. I wish you all fruitful conference deliberations.

May God bless you all.

I thank you.



His Excellency the President of Zambia, Mr Edgar Chagwa Lungu

Finally, Mr. Thomas Mtonga of Unza gave a vote of thanks to the President for the efforts that he and the First Lady of Zambia make in regard to issues of disability. He noted that according to WHO approximately 15% of any population are people with disabilities and he urged issues of disabilities to be mainstreamed and for the CRPD to be domesticated. He also encouraged policymakers to participate in conferences that address issues of disability, and thanked government for having successfully co-hosted the conference. Paddy Mukando gave the closing prayer.

#### **Keynote speakers**

#### Dr Liya Nawa Mutale, Permanent Secretary, Ministry of Community Development and Social Services

Dr Mutale gave an overview of the range of interventions in place in Zambia to support inclusion of people with disabilities including the social cash transfer system, rehabilitation services and access to education and training. She noted that: "Complementarity is better than distinct programme implementation. We are coming together and doing things together as one government. We can strengthen the mainstreaming of disability in all sectors we recently had a meeting of all Permanent Secretaries to stress the need to mainstream disability. We can also promote action research, support inclusive development through networking and collaboration, and encourage partners to invest in CBID".

### Dr Mutale posed four questions for the conference to consider:

- Do we practice inclusive development - do people with disabilities participate?
- How can we promote inclusive action research to make disability data easily accessible?
- How can we structure existing livelihood and empowerment initiatives for resilience building?
- How can education and training promote community based inclusive development?

#### Dr Alarcos Cieza, Coordinator, Disability and Rehabilitation Unit, World Health Organization (WHO)

Dr Cieza emphasized that at the last CBR Africa Conference she witnessed the discussion of whether we should embrace the name of CBID, and noted that CAN recognise CBID as the strategy but continue to be called the CBR Africa Network. Cieza noted that these conferences give the opportunity for participants to celebrate the work that they are all doing and to embrace the vision that is behind CBID – a world where people with disabilities have equal opportunities and experience social inclusion. She emphasized that the current international agenda is driven by the SDGs as a universal approach, and that CBID represents the targeted approach for people with disabilities to ensure that they are not left behind.

Dr Cieza emphasized that there are two strategies – CBID and rehabilitation. CBID is a disability agenda and needs to be led by the government ministry responsible for disability to address the lifelong needs of people with disabilities. It is a strategy about inclusion in all areas of life. Dr Cieza also highlighted that: "CBID should not be filling in service gaps. WHO is one counterpart in the UN system but only one. There are many other counterparts that need to be called on for their responsibility for CBID. All of them have an accountability to CBID".

#### Ms Ekaete Judith Umoh, Regional Chairperson, Disabled People's International (DPI), Africa region

Ms Umoh asserted that there still exists a lot of prejudice and discrimination against people with disabilities in the African society. However, she noted a recent paradigm shift from *"the patronizing and paternalistic approach to people with disabilities represented by a single medical model, to viewing us as members of the community with equal rights"*.

Umoh outlined the role of the CRPD at the international policy level, and the relevance of a twin track approach in working towards leaving no one behind. Such an approach should combine mainstreaming with programmes and policies that open up the space for effective participation of people with disabilities. She proposed the strengthening of government institutions and organizations of persons with disabilities to participate in democratic processes and other development efforts using the right-based approach (RBA). "Leaving no one behind requires specifics, either big or small practical steps that would increase visibility for the invisibles and amplify the voices of marginalized people in community development efforts".

#### *Mr. Mussa Chiwaula, Head of the Southern Africa Federation of the Disabled (SAFOD)*

Mussa Chiwaula noted the common assumption that if we have enough evidence that people with disabilities have needs that are not being met, governments will address them. However, this is not the case. He challenged participants to shift their focus towards innovation and entrepreneurship and to mobilize resources for people with disabilities at the bottom of the pyramid. He promoted a strategy that starts at the individual level by identifying and sharing innovations by people with disabilities as they try to access basic services such as water and sanitation.

Mussa asserted that CBR workers as the front line providers have often developed innovative programmes that can be replicated as future systems to be supported by government. He gave an example of a wheelchair 'repair and reuse' programme in Kwa Zulu Natal, which could be replicated in other contexts where huge piles of wheelchairs are in disrepair. Mussa urged delegates to put efforts into research to identify and share and shift discussion from problems and unmet needs to solutions that are addressing problems now. "Innovation is the key to sustainability. All CAN members should embrace innovation now. Share, learn and deliberate on innovations in the CBR sector".

The plenary questions and discussions on day one highlighted the role of capacity building for the shift from CBR to CBID. Participants and speakers noted significant gaps in capacity and awareness levels. One of the main challenges reported was the funding gap, as few donors support this area. The need to engage policy makers was also emphasized and participants were encouraged to review party political manifestos and hold politicians to account with reference to disability issues.

### *Huib Cornielje, Director, Enablement, the Netherlands*

Huib noted that for programmes to be

effective people with disabilities must be involved in all aspects. He highlighted the need for joint programming and implementation to achieve outcomes through sharing of knowledge, human and financial resources.

The findings of a study conducted in four African and two Asian countries were presented on developing essential standards for capacity building of CBR field workers, with the overall objective of building capacity in CBR. Huib stated that there is currently no consensus on the role and required competences of field workers, and therefore the objective of the study was with a view to developing a Guideline for essential capacity building of CBR field workers. The aim is to standardize core training to improve the quality of field work and subsequent outcomes. The research questions looked at the current profile, training curriculum and support system for fieldworkers in the six countries. The study found there was a lack of consensus regarding the core CBR competencies needed. The need for a functioning CBR support system was also emphasized.

#### Professor Gubela Mji, AfriNEAD

Professor Mji emphasized the need for Africans to divert from a parrot mentality and reflect on the issues raised with regard to disability. She urged organizations such as the African Union and the African Disability Alliance to form their own policies relevant to the African setting, given that all Africans were educated and their civilization is found in their own culture and heritage. Professor Mji also implored health professionals to clearly elaborate on the side effects of HIV Antiretroviral drugs that can cause disability. She observed that it was usual for young people to listen to adults given their knowledge and experience, and she urged participants to listen to people with disabilities in the same way – as people who through their experience know their needs, and can formulate their own research questions.

#### Hanna Fairs Billam, Co-founder, Tehilla Foundation Zambia

Ms Fairs Billam presented on the need to provide a safer environment for children with disabilities, and shared Tehilla's work to address child cruelty and violence in Zambia. It was reported that children with disabilities are more than three times likely to be abused or neglected than non-disabled children.

#### Shadrack Omol, Deputy Country Representative UNICEF – Zambia

Mr. Shadrack Omol emphasized the need to safeguard the rights of children with disabilities and highlighted that this was in line with the SDGs and the African Union development agenda. He mentioned that exclusion of children begins during childhood and is commonly more extreme for children with disabilities, who have limited access to education and health services especially in areas where these resources are scarce. Mr. Omol referenced the 2014 UNICEF Report on the State of the World's Children, which calls for action towards inclusion of children with disabilities and provides evidence of the success of children with disabilities when given equal opportunities with non-disabled children. He noted: "Children with disabilities have dreams, likes and dislikes just like nondisabled children." The Deputy Country Representative gave a list of three pledges by UNICEF going forward:

- To collaborate with Ministries of Health, National Development Planning and Community Development and Social Welfare, to ensure statistics on disability at birth are recorded and reported.
- ii. To collaborate with the media and politicians to raise awareness and strive to change attitudes towards disability in society.
- iii.To contribute towards provision of Social Protection given that it forms the basis of CBR.

In closing, he urged the delegation to make a list of three things that they will do to ensure inclusion for people with disabilities.

#### The First Lady of the Republic of Zambia: Mrs Esther Lungu

The Guest of honour Mrs Esther Lungu echoed the President's commitment to address the needs of people with disabilities in Zambia, and mentioned that she looks forward to the day when people with disabilities are more involved in the development of the nation. "Issues of disability have a special place in my heart". Mrs Lungu implored the delegation to review livelihood initiatives by involving people with disabilities and ensuring mainstreaming of disability in all aspects of planning, implementation and monitoring and evaluation. She also encouraged a further focus on strengthening legal policy frameworks and collection of data on disability. Mrs Lungu pledged to continue advocating for people with disabilities and urged all to rise to the challenge.

#### Vote of thanks from Mr Alick Nyirenda, Norwegian Association of Disabled (NAD)

Mr. Nyirenda referred to the First Lady as the country's ambassador for disability and stated that people were not baskets to be filled but fires to be lit. He thanked the First Lady for reminding the delegates that all people are disabled to some extent; therefore the need to interrogate data on disability to establish the true plight of people with disabilities. Mr. Nyirenda recognised the United Nations Agencies and cooperating partners' support and urged all countries to ensure that their Heads of States are part of the fraternity advocating for inclusive development including inclusive education and financing programmes for people with disabilities, so that "no one is left behind".

















# Workshops on cross-cutting issues

The first day of the CBR Africa Conference included five parallel workshops that gave delegates the opportunity to have in depth discussions on five key CBR/CBID topics.

#### Workshop: Government Representatives on the Future of CBID and Disability work in Africa.

### Moderator: Dr Abdul Busuulwa, Executive Director, CAN

This workshop was aimed at reflecting on how CBR has been implemented in Africa over the years and the way forward as we transition into CBID. The initial section of the workshop required participants to mention the existing challenges within CBR and they listed the following:

- lack of up-to-date data on disability and people with disabilities
- poverty status of people with disabilities and their families
- widespread exclusion of people with disabilities from education, employment opportunities and health
- negative attitudes against and among persons with disabilities
- marginalisation of disability programmes such as inadequate funding and poor planning
- non-representation of people with disabilities in government structures
- lack of awareness and implementation of existing laws and policies relating to disability
- lack of access to the physical infrastructure and information
- there is a a disconnection between the work of DPOs and that of governments.

The following were the possible causes of the above challenges, as given by the workshop participants:

- parents tend to stigmatize their children with disabilities
- lack of understanding of disability by data collection officers
- there is no standardised definition of disability
- many programmes have multiple recipients; hence making it hard to know whether or not people with disabilities are involved
- limited services for the prevention of disability and rehabilitation of persons with disabilities, resulting from late identification of disability
- lack of funds allocated towards disability.

#### Delegates discussed the issues raised and formulated the recommendations below for successful CBID implementation:

- people with disabilities to advocate for inclusiveness in development through networking with decision-makers
- empower DPOs to play a central role in CBID initiatives.
- adopt and standardize CBID Guidelines that have been successfully implemented in other countries such as Nigeria
- facilitate advocacy and awareness raising programmes through the media
- promote systemic collection of demographic statistics at birth to facilitate early identification of disability and care
- adopt the bottom-up approach to planning and implementation of programmes through involvement of communities





- share information on CBID initiatives and planned activities to reduce fragmentation of rehabilitation services.
- build working relationships/partnerships among CSOs, DPOs and government to reduce the vulnerability of Persons with Disabilities

# The workshop also proposed the following recommendations with regards to disability Focal Point Persons (FPPs):

- ensure that FPPs fully understand issues pertaining to disability and persons with disabilities
- ensure FPPs fully understand their role
- ensure that senior most officials in relevant government Ministries, Departments and Agencies are selected as FPPs.

Having proposed recommendations and action points going forward, delegates were called upon to ensure inclusion of people with disabilities at all levels in all sectors.

# Workshop: Facilitating and coordinating implementation of disability research evidence in Africa.

#### Moderator: Callista Kahonde, AfriNEAD

Callista Kahonde explained that research is about understanding the world in order to contribute to changing it. Research increases the quality of information available to us. It is an organised and systematic method of finding answers to questions: Systematic because it is a process broken up into clear steps that lead to conclusions. Organised because there is a planned structure or method used to reach the conclusion.

Participants were asked to discuss in groups, problems they encounter in their CBR/CBID work and solutions they found to those problems. It was noted that in the past the focus of disability research was on medical issues but empowerment, networking and activism is now leading to more inclusive research.

Emancipatory disability research was discussed. It was noted that emancipatory research strives for change, informed by a framework of social justice, equity and citizenship for persons with disabilities. This type of research is useful and relevant to those whom it is intended to serve, and people with disabilities are empowered through the use of the knowledge and expertise of the researcher. There is a need for trust, respect and commitment, and the researcher and people with disabilities are equal partners in the process. It is about moving from research that serves the agendas of politicians, policy makers and professional academics to being accountable to and conducting research that aims for empowerment of persons with disabilities.

The workshop emphasized that people with disabilities should be given space to do research work in any field - not limited to research on disability only. People with disabilities should contribute in discussions in the villages and on all development issues. They must participate as human beings and not as persons with disabilities. The presenter stressed that if communities are educated on disability movements, they can change the way they think. Most research evidence aims at policy shift and leads to change. The moderator emphasized that the question each stakeholder should ask him or herself is what do people with disabilities want from research?

#### Workshop: Transitioning from CBR to CBID: a journey for sustainability and ownership of CBR programmes.

#### Moderator: Soumana Zamo

Soumana Zamo listed the four objectives of the transition from CBR to CBID for CBM as to:

- achieve community inclusion
- ensure local government and other service and support systems are inclusive and functioning effectively
- create accessible and disaster-prepared communities
- ensure effective monitoring, evaluation and research.

Mr. Zamo highlighted that the transition is there to create an environment where communities become more inclusive, resilient and participatory. An environment in which people with disabilities are included and local government and other support services can function effectively. The CBM action plan includes capacity building of key CBM and partner staff, together with coaching/technical support to enable their partners to align their programmes with wider development and human rights frameworks in their countries, while contributing to global learning and progress.

### A number of questions arose from the presentation including:

- How do we link the knowledge and research to this transition?
- Does the transition mean there will be plans for inclusion of people with and without disabilities and how will the cake be shared?
- What exactly is changing, is it the name or strengthening social aspects?

Soumana explained that "the move from CBR to CBID is an evolution not a revolution". It is about improving on the shortcomings and responding to changing policies and regulations. Research is included within one of the four objectives and this will include a review of what has been done and what is needed. The evolution is also about improving the processes of inclusion from the conceptualizing stage to the implementation and ensuring that all people benefit – not just people without disabilities.

#### Workshop: Developing Essential Standards for capacity building of CBR field Workers.

#### Moderator: Huib Cornielje, Enablement

This workshop was modelled on the findings of a study on what could or should be considered as essential functions in CBR; What are the essential tasks of CBR field staff and thus what essential competencies do CBR field staff need or what essential training is required to be given to CBR field workers.

The workshop took the form of the 'World Café' where participants were divided into seven groups, who moved from one station to another addressing a single question in each group. One group member remained in each group for continuity. Eight questions were posed to participants:

- 1.What are the ten most important competencies that field workers should master?
- 2. In order to be meaningful in livelihood CBR field workers should have relevant competencies: which ones?
- 3.What is the strongest impact and what is the largest shortcoming in the day-today work of field workers? How to address this and improve even more the impact?
- 4. What further research is needed in order to strengthen the competency base of field workers?
- 5. How can supervision increase and improve the impact of the field worker: system and skills of the supervisor (including from which background (health, education, DPO, social work)?
- 6.What is the role and what are the competencies of the CBR supervisor in order to improve the impact of the field workers?
- 7.What should be the minimum length of training and set-up of training?
- 8. How to get government recognition of fieldwork training?

All groups had lively debates about the topics and an opportunity to present their views and perspectives. Huib explained that the questions had been asked as part of a research study in six countries: Burkina Faso, Malawi, Tajikistan, Uganda, Vietnam, and Zambia, the results of which would be presented the following day during his scheduled plenary session.

The workshop noted that the CBR field worker may not have all the skills but there was a need to identify the priority skills in which they can be trained. The conference highlighted the need for documentation, which is often lacking, and for systems of coordination. The workshop also raised the need for standards in the curriculum of the CBR trainings.

#### The session concluded that:

- capacity building is critical in the skills for CBR field workers
- there is need for standards for CBR trainings and curriculums.

### Workshop: Development of CBID training packages

#### *Moderator: Dryford Mpunga, Malawi Council for the Handicapped (MACOHA)*

Dryford was supported by a team of the CBID trainers: Eunious Chirwa and Simon Munde, (Malawi), Caroline Malala Hamankolo, Eddie Mupotola and Alick Nyirenda (Zambia)

Dryford Mpunga presented the background to the development of the CBID training packages. He explained that in Malawi CBID programmes were historically fragmented with different stakeholders using different models. However, MACOHA, in collaboration with other stakeholders, developed a new harmonized CBID model coordinated by government that could better respond to the needs of people with disabilities. It was identified that implementation of the new model required building the capacity of all stakeholders at national, district and community levels and this was the catalyst for the development of the CBID training packages.

The packages were developed between 2016-2018 in collaboration with Flourish

Consulting UK who blended local knowledge and materials with international resources to come up with guality, standardized materials relevant to the Malawi context. Stakeholders participated in identification of the topics, reviewing and pretesting of the modules. The Norwegian Association of Disabled (NAD) supported the process. A national Training of Trainers (ToT) was carried out to develop a team responsible for training personnel within all the District Councils responsible for implementation of CBID. The training team includes people with disabilities and all training resources are being produced in braille. The district trainers are responsible for training community CBID cadres, mostly extension workers working with people with disabilities and their families at the grassroots.

Alick Nyirenda explained how the CBR programme in Zambia had collaborated with the Malawi team and the consulting company to domesticate the training for the Zambia context. A workshop was held to review the materials and consider areas to be expanded or changed, and pilot trainings have been conducted. This process is ongoing.

Sample modules of the training were delivered to participants of the workshop by a combination of the Malawi and Zambia trainers. These included a participatory process of looking at the five models of disability: the traditional model; charity model; medical model; social model; and rights based model. Also an activity called 'language and labelling' was carried out with participants to look at the language people use to describe people with disabilities. There were more than 15 African countries represented in the room, and the activity highlighted that across Africa, language is invariably very negative and stigmatising, and the need to use positive language and using people's names rather than identifying them by their disability was emphasized.

There was great interest in the training packages from participants. Mpunga explained that when final revisions and consolidation of the training packages is completed later in the year, the packages will be made open source and available for other organizations to use.

# Main conference topics

The following section provides insights into some of the presentations given under sub-themes of the conference, as well as questions and discussions around the presentations.

## Action research, documentation, and information sharing

More than ten speakers addressed this topic covering a wide range of areas. Dr Jack Chola Bwalya reported that in Zambia empirical studies have shown that people with disabilities are disproportionally underrepresented in political life and face numerous challenges to active involvement in political affairs, including the simple task of voting. In spite of developments such as 'e voting' in some countries, the participation of people with disabilities is not increasing. Their study explored the relationship between demographic characteristics and Zambian peoples' opinions around voting for a political candidate who has a disability. They reported that although 62% of respondents said they would vote for a candidate with a disability for political office, they found that groups less likely to vote for a political candidate with a disability are young people and less educated people.

Evelyne Huizinga from Malawi presented results from a study that looked at the effect of a CBR programme on perceived activity and participation limitations of people with disabilities in Malawi. The study found that approximately 50% of people with disabilities reported improved functioning, and of those 20% reported full recovery or significant improvement. Children with higher levels of functioning seem to gain the most from CBR initiatives; those with mild physical disabilities and children who can communicate verbally do particularly well. Dissatisfaction was shown mostly regarding effective communication and the low number of home visits. Respondents reported the main impediments

to attending sessions as logistical challenges such as transport, mobility issues, caregiver support and poor communication. The provision of assistive devices was significantly associated with improvement, emphasizing the need to work collaboratively with other programmes and for provision of appropriate assistive devices to be an essential component of a CBR programme. Their study found that partnerships with other service providers and multi-disciplinary interactions were most effective.

Martha Banda Chalwe's presentation also measured performance levels, focusing on the use of the ICF in measuring performance of basic activities of daily living in people living with HIV and AIDS in two selected home based care programmes in Lusaka, Zambia. The study found that most participants experienced mild to moderate levels of pain, numbness and fatigue in achieving basic activities of daily living.

Sharon Handongwe from Zambia noted that it is acknowledged that the most serious issue faced globally by people with disabilities is not their specific impairment, but rather their lack of equitable access to resources and services such as education, employment, health care and social and legal support systems. Her research looked at why people with disabilities have challenges accessing services despite the statutory provisions on disability provided at international and national levels. Barriers noted by the study were the lack of information on statutory instruments (only approximately 50% of survey participants were aware of the statutory instruments), as well as a lack of information on human rights and cultural barriers. Facilitators to inclusion suggested more support and acceptance from family and community, provision of skills training, access to assistive devices, and greater sharing of information on human rights and instruments.















Musola Kaseketi of Vilole Images Productions, also emphasized the need to promote the issue of human rights. Her organization focuses on disability rights of women and girls in Zambia and she presented a series of films she has produced as a way to use the power of art to carry out advocacy for the rights of persons with disabilities, stressing that this is a powerful medium to raise awareness and positively change attitudes.

Many speakers reflected that a conducive physical environment would enhance school attendance among children with disabilities and subsequently overall inclusive education. Awareness creation and attitudinal change about disability issues were mentioned as needed across the continent by speakers, and reinforced by delegates in the question and discussion sessions. Reporting on the situation in Rwanda for children with disabilities, Jean Baptiste Sagahutu, University lecturer in the University of Rwanda noted that children with disabilities generally do not receive any education at all, or if they do it is frequently inappropriate. Underlining findings from other countries, barriers to access in Rwanda were listed including long distances from home to the nearest school, and the status of the physical school environment. The study also found a negative attitude among parents and the community towards children with disabilities. It was generally agreed that community involvement and support is critical to achieve inclusive education.

NGO Congo Handicap recommended teacher training in the language of signs and Braille, advocacy to adapt exams to different types of disabilities, and awareness raising among student representatives on the need to report the existence of learners with disabilities to teachers and reserve priority seats. They also proposed awareness of learners with disabilities on self-esteem, as well as specific and individualized assistance.

Many speakers also highlighted the importance of supporting the development of DPOs and their meaningful involvement in CBID programmes. Pascal Ahidjo reported on the lessons learnt through development of self help groups in Cameroon and noted that "while 'self-help' might imply a focus on the individual, an important characteristic of self-help groups is the concept of mutual *support – people helping each other."* Ahidjo emphasized that participating in self-help groups can improve the visibility of people with disabilities within their communities and provide them with mutual support. It can also encourage them to share resources and find solutions together, and empower them through increased confidence and self-esteem. Ahidjo reported on the historic situation of NGOs, churches, and missionaries taking a welfare approach and providing handouts or goods, creating a context where group members expected to receive something. He noted that the challenge for the CBR worker was to sensitize the members that their empowerment needed to come from themselves. In Cameroon support was provided on the creation of groups, as well as their structure, leadership, group management and advocacy skills and follow up has provided ongoing support and guidance. Ahidjo suggested a number of considerations for groups to function well including investing in group leadership, and identifying what motivates people to join. He also stated that their experience had found that sustainability was greater where selfhelp groups were linked together and that to achieve outcomes up to national government level, self help groups need to be represented at those levels.

FANILO CBID in Madagascar also support organizations of people with disabilities, such as people affected by the cyclone, and they reported on their programme which includes sensitization and training for the authorities of the municipality to adopt a clear policy to manage and reduce disaster risks due to natural disasters. Fanilo use a dual track strategy of advocacy within the community to change the mindset and adopt an inclusion policy as well as personalized project actions for people with disabilities and their families according to their needs – including on-thejob training as well as support for people with disabilities who already have an incomegenerating activity such as bicycle repair, forging, or carpentry, with, for example, tools and materials. Delegates from across the continent confirmed the importance of supporting DPOs and many added their own examples through the discussion sessions.

Several speakers looked at the appropriateness of different actors within CBID. Regional group AfriNEAD promotes engaging people with disabilities and researching through them and with them, not only about them. This is achieved through planning and implementing collaborative research projects involving persons with disabilities, academic researchers, government officials and civil society. Currently, AfriNEAD is using assistive technology as a research focus area in coordinating the country working groups, in line with the World Health Organisation (WHO) Global Cooperation on Assistive Technology (GATE) Project whose vision is to ensure that high-quality, affordable assistive products are accessible for people to lead healthy, productive and dignified lives.

Shaun Cleaver of McGill University looked at the question of whether 'Northern' actors can facilitate inclusive local development and found that in some cases project and context features can prevent inclusive local development.

On the topic of documentation, Eunious Chirwa from MACOHA in Malawi presented a Disability Management Information System (DMIS) and Monitoring and Evaluation framework designed to strengthen the collection, analysis, and sharing of data in the Malawi CBID programme. The aim is for local councils to be able to use the tools. However, significant capacity building is required at all levels, as disability knowledge remains low.

Some speakers presented on the needs of people with specific disabilities. Dr Groote Wouter of the International Federation for Spina Bifida and Hydrocephalus and Child Help explained that they have developed training materials and tools for persons with disabilities, Parents and CBR workers to support the management of people with Spina Bifida and Hydrocephalus. He emphasized that for these disabilities physical rehabilitation is needed early, as these conditions may present with many complications.

The discussion around the Action research, documentation and information-sharing topic between speakers and participants emphasized that there is a benefit in focusing on locally initiated policies such as the African Protocol on the Rights of Persons with Disabilities. Also the need for accessible formats and local language translations was emphasized. The need to involve the media was discussed, to help raise awareness of disability issues and educate the general population. The role of DPOs and self-help groups was acknowledged by many of the participants and it was emphasized that efforts should be made on documenting best practice and lessons from various interventions. It was also stressed that more research is needed in many areas, and that monitoring and evaluation should be built in at the start of a project.

There was general agreement from participants that the main challenge in Africa is how to implement inclusion where even services are not available.

The difference between CBR and CBID was also discussed and one speaker summarized that CBR was about service delivery while CBID was about inclusion. Another highlighted that CBR was focused on the person with a disability and the family, but now CBID is broader and encompasses development for the greater community. It was also emphasized that CBR ceased to be medical when the CBR Guidelines and Matrix were developed and that all CBR Matrix areas must be addressed at the same time.

Some of the main recommendations to be made by delegates in relation to this subtheme were that there is a need to enhance the domestication of The African Charter and the Protocol on Disability, which is Africa's own context policy. The value in investing in media engagement in order to deal with the perceptions of the general population regarding disability was also emphasized. Furthermore, it was widely noted that there is a need to invest in further research in order to address the revealed knowledge gaps. Many delegates emphasized the important role of self-help groups, as well as the value in documentation to capture lessons learnt and best practices from various interventions.

# CBR/CBID training and education

The topic of CBR/CBID training and education generated a lot of interest at the conference. Carolyne Maholo of Kyambogo University in Uganda emphasized that CBR training is the key to resilience building, and is about developing the capacity of individuals, organizations and communities to identify their challenges, threats, and opportunities, their existing resources and facilities to facilitate transformation of their lives. Maholo noted the importance of training trainers, people with disabilities, family members, service providers and policy makers.

Jacques Chirac of Cameroon also discussed the role of multiple stakeholder engagement. Chirac reported on sustaining inclusive education in the 'Socio Economic Empowerment of People with disabilities (SEEPD)' Programme in Cameroon. CBID was used as a strategy to pilot inclusive education (IE) in 18 primary and secondary schools, through advocacy, education, sensitization and empowerment of different stakeholders including teachers, school administrators, parent-teacher associations, school councils, students, parents and municipal authorities. Stakeholders are undertaking different but complementary activities to ensure the implementation of IE. Results have been positive with attitude change seen within communities towards people with disabilities and increased enrolment and achievements of children with disabilities and construction of more accessible structures. Chirac asserted that "IE is a public action which requires collective and purposive cajoling of the public". One of the challenges mentioned was the breakdown of assistive devices without a corresponding capacity for repair. For example, while Braille embossers are required to facilitate brailing, there are no existing capacities for their maintenance. Also, the absence of an integrated M&E system posed profound difficulty in planning transitions for learners from one level of education to the next.

The University of Gondar in Ethiopia reported on an initiative where they have recently

partnered with the International Centre for the Advancement of Community Based Rehabilitation (ICACBR) at Queen's University in Canada to develop a CBR certificate programme at the University of Gondar, and also on a pilot project to address child protection through targeting four groups within established structures: the government office of women and children's affairs; the community care coalition; teachers of children with disabilities and children with disabilities themselves.

Many speakers focused on the importance of training parents and carers of children with disabilities. Lameck Saka of Motivation in Malawi reported on a programme to train community level facilitators to support children with cerebral palsy and their families using a 'Get to Know Cerebral Palsy' training package to teach well-tested techniques and methodologies to parents and caregivers. Community workers from CBOs and CBR are also trained on referral and community follow up processes to better support wheelchair services and wheelchair users including children with cerebral palsy. The results have been positive, with parents able to evaluate developmental milestones of their children and community members becoming more aware of cerebral palsy and supporting the children and their families. Disability related myths including witchcraft beliefs are being demystified and discrimination is reducing as attitudes change.

Comprehensive Rehabilitation Services in Uganda (CoRSU) are also addressing the issue of building positive mindsets of parents of children with disabilities through CBR training, tackling the stigma and negative attitudes that disable individuals, as reported by Moses Kiwanuka.

Etenesh Wondmagegnehu talked of CBR as a bridge to inclusion in Ethiopia where they have been building the capacity of extension health workers to reduce barriers to children's full inclusion.

The Provincial Department of Ministry of Social Affairs, Sofala Province, Mozambique presented on the strategy to include a CBR module as part of the standardised training for social workers, based on their role in the national CBR strategy at district level. The provincial department has started to offer a two-week module in CBR to all social workers trained in Beira since 2014. Module topics include the CBR Guidelines, the history of CBR, implementation of CBR activities, especially livelihood and social inclusion, as well as inclusive education and making local appliances in the community. Since the start of the CBR module there has been an increase in the identification and referral of people with disabilities to the relevant sectors in the districts, showing the value of the module even where there is not yet an official CBR programme in place.

Wukwashi wa Nzambi in Zambia run a parents forum to provide information as well as providing training in the communities to raise awareness about disability and the potential and rights of children with disabilities. They also run a 'pathways' school, in many cases preparing children with disabilities for mainstream education and vocational training.

Inclusive education (IE) issues featured highly within the conference. Many speakers highlighted limitations in terms of physical environments, teacher skills and the presence of negative attitudes. Kyambogo University in Uganda are partnering with The Royal Dutch Vision on a programme to enhance full participation of low vision secondary school students in society. Maholo and Nganwa reported that most of the efforts in special needs education and disability inclusive education have been directed to primary school education, and at secondary school level resources are very limited. They found that identification, assessment and screening of students with low vision is lacking and many children who would benefit from low vision assistive technology are forced to cope with equipment and facilities for blind people, which restricts maximization of their learning potential. Francis Simui from the University of Zambia presented on a 10-year trend analysis of children in special education in Zambia and noted that most children with disabilities are still outside the education system, and those present are largely absent in terms of participation and achievement. He called for achievement of inclusive education as reflected in the UNCRPD and the Disability Act.



Continuing on education, a case study presented by Mubukwanu Felistus listed nonuser-friendly infrastructure, long distances to school, and lack of appropriate skills among teachers for handling pupils with disabilities as major challenges faced by pupils with physical disabilities in accessing inclusive education. Mr. Mpolomoka's presentation from Zambia reinforced these findings, noting that negative attitudes of school administrators, teachers and fellow learners of people with disabilities, as well as rigidity in teaching approaches and unsuitable teaching/ learning materials are major challenges. It was reported that initial teacher education offered in teacher training colleges is not adequate to equip teachers with inclusive schooling teaching methodologies. Findings also indicated that Continuing Professional Development (CPD) is not systematically implemented specifically for teachers handling learners with diverse needs in inclusive schools. From Tanzania, Said Juma also noted that teachers in many sub-Saharan African countries seldom get an opportunity to collaboratively reflect on their practices. He proposed that Action Research as an inservice teacher education strategy can be an ideal means of empowering teachers.

Questions and discussions on this topic

emphasized that inclusive education is not just about disability but ensures that children with disabilities and non-disabled children learn from each other about all topics.

In relation to CBR/CBID training and education, participants widely recognised through the discussions and question and answer sessions that capacity building is critical in developing the skills of CBR/ CBID field workers and that there is a need for standards for CBR/CBID training and curricula. It was underlined that CBR/CBID practitioners need to involve beneficiaries in the identification of their needs and that assessments and research should be conducted regularly on the situation for people with disabilities to monitor changes and identify priorities.

# CBR, gender and child protection

Ethiopian organization Berhan Lehetsanat asserted that "Education for All" is only a motto that cannot be fulfilled without a link between home and school. They underlined the need to provide any necessary medical, physiotherapy, home based education, and assistive devices in order to create access to education for children with disabilities. Their research findings identified that the existence of CBR in the project areas improved the interest and capacity of teachers to support students with special needs, and access to education for children with disabilities reached 60% compared to a national rate of just 4%. The CBR interventions are taking place at different levels including sensitization of government officials and policy makers on creating a barrier free environment, training higher institutions that train teachers, awareness raising training to community members on issues of accessibility, media campaigns, and confidence building for people with disabilities.

The Harmee Education for Development Association (HEfDA) from Ethiopia piloted child protection as part of its disability inclusive development programme in 2017. They identified substantial violence against children taking place in the community including physical abuse, sexual abuse, labour abuse, psychological abuse from parents, and child trafficking for forced labour. They found that the legal system was not taking cases of abuse seriously and most perpetrators were not punished. Furthermore, parents had little awareness on the harm of violence to the development of their child. Children with disabilities, orphaned children and children from the poorest families were identified as the most vulnerable to abuse.

The pilot provided awareness training to community members and local officials; community discussions amongst parents and local government leaders; and formation of groups to raise community awareness. Child protection structures were formed in the community including capacity development of stakeholders (including the legal system) on child protection and establishment of selfhelp groups of parents in the most vulnerable groups. 40 children were also trained as peer educators on issues of child abuse and child protection and 400 children trained on child protection including 40 children with disabilities.

In addressing child protection, Vision **Community Based Rehabilitation Association** (VCBRA) started within their own organization with the development of a child protection policy and knowledge sharing regarding safeguarding children with disabilities from harm. This expanded to work through the CBR programme with parents, government officials, and through establishment of child protection clubs. Many parents did not realise that some of their actions were violating the rights of their children. Child to child clubs were set up where children teach children about their rights and protection from violence. 22,550 children with and without disabilities were reached in the pilot.

Joseph Munyandamutsa, founder of CECHE Foundation in Rwanda, reported on a CBR programme training parents of children with disabilities through a strategy where each village has identified one parent as a Community Inclusive Development Worker, whose role is to identify impairment in early childhood, refer to service providers and link the family with community inclusive developmental initiatives. Parents are encouraged to play a role in making affordable supportive devices for children with cerebral palsy using community resources such as appropriate paper based technology (APT) and are also supporting each other in income generating projects and family events. Parents with children in need of rehabilitation support are taught home based care. *"Engaging parents in every step of programme development has contributed to inclusion of children with disabilities in the community"*.

Delegates from many countries of Africa shared their insights into the issues of gender and child protection in CBID. It was reported that in many cases women with disabilities are not consulted regarding gender policies and the result is that they are ineffective. The issue of the police requesting payment to investigate issues of abuse against women and children was also raised as a challenge. With regard to mothers abusing their children there was wide agreement that education and awareness raising is key. Government were also urged to take a more active role in these issues by many participants.

# Livelihood initiatives for resilience building

**OREBACOM**, from Beira, Mozambigue are reaching more than 1500 people with disabilities through their programme supported by Light for the World. Their collaboration with vocational training centre 'Young Africa' is improving livelihood opportunities for young people with disabilities identified by the CBR programme. Many people with disabilities in Mozambique have not been to school and entry requirements represent a major barrier for participating in vocational training or other courses. OREBACOM has focussed on helping people with disabilities to gain the needed literacy skills for some of the courses offered, as well as negotiating with Young Africa to include people with disabilities where literacy is not essential or limited literacy skills are required. Young Africa has trained their trainers in sign language, and now employ sign language interpreters for courses where required. Ramps have been built within the facility, and 'Jaws' software added to the computers to improve access for people with visual disabilities. All staff from OREBACOM's partner Young Africa also received training

about the UN CRPD and how to support people with various disabilities in the training courses, and many have gone on to secure formal employment, or are self-employed or have set up small business.

FANILO in Madagascar are implementing a CBR livelihoods programme with the technical and financial support of CBM. Its objective is to work for inclusive development and socio-economic reintegration of people with disabilities. Light for the World's programme in Mali is focusing on income-generating activities for women with disabilities or mothers of children with disabilities and includes management training and provision of grants. They underlined the importance of training for success, and how participation has led to a change in the community's view of the women, who now feel more valued.

Dr Khondowe of Lusaka Apex Medical University, Zambia presented on a research study to appraise evidence on the effectiveness of livelihood interventions on poverty reduction among persons with disabilities. He stressed some of the main challenges of livelihood interventions, which the research identified as including:

- lack of consequence for those who do not return loans
- social Transfer funds are too small
- abuse of funds
- mismanagement of programmes
- access to loans and access to funds for establishing a business
- many potential lenders incorrectly perceive people with disabilities to be a high risk for loans.

Hubert Seifert, CBM Senior Advisor for Livelihoods, reported that CBM is supporting 640 programmes in 63 countries including 123 programmes that include a livelihood component. Seifert listed challenges of conventional livelihood interventions in CBR/ CBID, which include start up grants that tend to perpetuate the charity model and have low-impact, as well as disability specific micro-loan and revolving fund programmes that often fail due to the lack of capacity for their management. A Village Savings and Loans Association (VSLA) concept developed by NUDIPU in Uganda and supported by NAD has formed over 1,000 groups with 30,000 members and supported the start up of 13,000 income generating activities. The concept combines group training, development of a constitution, election of officials, setting of targets and structures, transparent and robust financial control systems. A CBM supported VSLA programme in Rwanda with NUDOR has a target of establishing 560 groups, and in Ethiopia a programme with ORDA is targeting 14,000 people. Benefits of VSLA programmes include:

- VSLA groups make people with disabilities more visible in communities contributing to changing people's attitudes
- increases opportunities for unemployed persons to start businesses and increase farming income
- participation increases self-confidence and self-esteem
- group members work together to solve problems.



In Zambia, the Sani Foundation are promoting training and employment opportunities for people with intellectual disabilities, recognising that they are the most marginalized in the labour market. They are using work-based learning - providing students with real-life work experiences where they can apply academic and technical skills in order to develop their employability skills. The support is individualised and uses 'supported' rather than 'sheltered' employment opportunities. Training is offered in a wide range of job-skills and competences oriented to the Zambian open labour market, and provides social skills training through interactions with others.

Abdou Yohanna explained how the Leprosy Mission in Niger is supporting people affected by leprosy through training on management techniques to carry out income-generating activities (IGAs). The Zambia Federation of Disability Organisations (ZAFOD) and the Mental Health Users Network of Zambia (MHUNZA) have been working to advance the human rights and inclusion of people with psychosocial and intellectual disabilities by piloting a community development approach in the three communities of Mansa, Kazungula and Shangombo. The aim is to demonstrate the implications for livelihood development when people with disabilities are supported to exercise their right to legal capacity at the grassroots level.

Though the discussions were around presentations, many delegates shared their own experiences of successes and challenges relating to livelihood initiatives. Delegates from various countries identified a common challenge of bad debts incurred as a result of beneficiaries' failure to pay back loans. It was also noted that DPOs invariably do not have the specialist know-how to successfully manage loans programmes. In this regard, the conference noted the need to engage Microfinance institutions to manage loans on behalf of the organization.

# CBR/CBID in a humanitarian crisis

Action Amos, of FEDOMA in Malawi presented on the voices of people with disabilities in disaster risk reduction in southern Africa. He reported that natural and man-made hazards such as climate variation, epidemics, and economic crises cumulatively affect thousands of people in Southern Africa, and yet disaster risk reduction stakeholders generally have little knowledge or commitment to make their plans disability inclusive. Challenges for people with disabilities in a disaster situation include structural barriers, lack of information in accessible formats, and absence of selfrepresentation in disaster risk reduction planning.

Simon Munde of FEDOMA presented on the role of the CBID empowerment component

in disability inclusive disaster risk reduction (DiDRR). He highlighted that through the Sendai Framework for DRR, governments are now called upon to engage with relevant stakeholders including persons with disabilities, in the design and implementation of policies, plans and standards. FEDOMA's DiDRR initiative is ensuring the inclusion of people with disabilities in Civil Protection Committees and other development committees. People with disabilities are oriented on the evacuation routes to be used during disaster and the importance of people with disabilities being evacuated with their assistive devices is emphasized.

In general it was agreed through the discussions surrounding the presentations on this sub-theme that the needs of people with disabilities have historically not been addressed. Delegates welcomed the increased attention to this area and it was agreed that participants should continue to advocate for the inclusion of people with disabilities in all aspects of planning and dealing with humanitarian crisis

#### Neglected tropical diseases and CBR

Carolyne Maholo and Barbara Batesaki presented a study that looked at the inclusion of people affected by Leprosy and Lymphatic Filariasis (LF - commonly known as elephantiasis) in generic community development. They reported that in Uganda, numbers of people with both disabilities were increasing, including within children of school going age. The increase is attributed to lack of knowledge and information on how they are transmitted and the negative attitudes that arise from ignorance of the conditions. The research identified that people with Leprosy and LF are excluded from both disability programmes and from general community development programmes.

Mohamedi of Tanzania reported that "community in general is lagging behind on knowledge about leprosy, its treatments and results and this is the main reason people affected by leprosy continue to suffer discrimination". For the last three years the Leprosy Association in Tanzania has invited people with disabilities to meet with people affected by leprosy to participate, dance together and eat together from the same plate to educate people through songs and speeches. This has encouraged the community to develop a proper understanding of leprosy and show respect for the human rights of the individuals and families it affects.

Raphael Mulamba of The Leprosy Mission (TLM) in DRC reported that the Democratic Republic of Congo has the highest prevalence of leprosy in Africa and is 4thin the world with 4,237 new cases reported in 2016. He stated that people affected by leprosy are isolated and stigmatised, resulting in their exclusion from opportunities. TLM's programme is addressing needs through six areas: health care, provision of assistive devices, education, livelihood initiatives, advocacy and promoting active participation in community activities.

Terver Anyor of The Leprosy Mission Nigeria discussed the strengthening of health systems for accessible and affordable care for neglected disease sufferers who are frequently marginalized. The Leprosy Mission Nigeria have worked to strengthen health systems through human resource development, improving health infrastructure, strengthening referral systems, enabling access to information and supporting community groups to prevent and recognize common neglected tropical diseases.

Overall the discussions on this topic emphasized that people affected by neglected tropical diseases such as leprosy are routinely stigmatized and isolated. There are many misconceptions concerning their conditions and they are frequently not included in disability programmes.

# Ownership and sustainability of CBR programmes

Chirac from Cameroon discussed the issue of partnering with local government units to sustain community sign language in Cameroon. Before 2015, with the use of standard sign language, community based pre-school support was given to children with hearing impairments, their families and communities by field workers who moved to individual homes to teach sign language.

Over time families and communities become passive thus necessitating a change of approach. The presentation showed how CBR staff can sustain community sign language in resource limited settings. Seven municipalities with an average of 13 children with hearing impairment were identified and from a rights based approach, sensitized on the importance of promoting sign language within the wider community. Municipal authorities partnered with the sign language resource centre to organize community sign language workshops. Registration was required of all participants at a rate of 2 US Dollars per person. Almost 100 children with hearing impairment, 270 community members and families participated actively in workshops and acquired basic communication skills. All participants were provided sign language DVDs to facilitate home learning. This also led to the designation of sign language focal persons in councils and the celebration of international week for the deaf by councils. The presenter concluded that the involvement of local government structures is a sustainable way to run a CBR programme, and that when cost is added to any service, it can be more highly valued.



In Rwanda, a twin track approach ensures that the general objective of promoting disability as a cross cutting issue and ensuring that all development actions include a disability perspective and are fully accessible is accompanied by disability specific actions to increase the empowerment and participation of people with disabilities. A multisectoral CBR/CBID structure is in place and the government is taking the lead in coordination. Joseph Gona introduced Project SEEK, a project which has established 20 selfhelp groups in Kilifi County, Kenya. There was an extended set up phase to enable the development of the membership, group identity, and distribution of roles and income generating activities. The structure of meetings was guided by the recommendations of the CBR Guidelines. The formed self-help groups were required to initiate projects independently to address problems members faced. Start-up projects included merry-go-round activities, sharing of foodstuffs, making 'makutis' (thatching materials) for sale, keeping local chickens, table banking activities, making brooms from coconut fibers, and soap making. A facilitated intervention was developed to support group engagement with a range of relevant topics that featured in their lives. This included topics such as economic empowerment, sharing of personal situation, peer support, community inclusion, access to health, and access to education - which were introduced one by one to the self-help group at monthly intervals. Interviews held with participants identified that before the intervention, the caregivers expressed a strong sense of the burden of caregiving and talked of feeling alone with their troubles and lacking support. Many experienced stigma in their communities. After the intervention there was a much stronger sense of caregivers being together and working together. Related to this was their development of skills in problemsolving and a general view that their lives had improved because of their participation.

Nelson Sakala highlighted that cultural issues are part of the source of stigma and discrimination that people with disabilities frequently face and the study he presented sought to locate the place for traditional leadership in Community Based Rehabilitation. The presenter argued that CBR programmes should include traditional leadership as long-lasting leaders of their communities who, unlike implementers, cannot easily disengage from the programme once well equipped and trained.

Alick Nyirenda of the NAD CBR Zambia Support Programme reported on the successes of a twin track approach of working with government and DPOs/NGOs and parent support groups to build knowledge, skills and capacity. He emphasized the need now for scaling up CBID in Zambia and finding ways to motivate and support volunteers and institutionalize training of CBR workers and teachers.

Huib Cornielje noted that in low and middle income countries the social aspects of inclusion for children with neurological disorders / cerebral palsy are increasingly better addressed in CBR programmes but the medical and technical aspects frequently remain at a low level. Field workers often stick to routine 'exercises' that may even be harmful. There is also a lack of quality tools for parents. The goal of the project isto increase the quality of assessment and goal setting among fieldworkers to improve the quality of rehabilitative services for children with neurological disorders and their caregivers. An 'Assessment App' and standardized tools are being developed as well as a Training of Trainers package. Fieldworkers will be trained in assessing children with neurological disorders; setting goals for (functional) rehabilitation; and where necessary referring children for access to assistive devices and/or medication.

Shaun Cleaver identified that North-South partnerships are often presented as mutuallybeneficial arrangements for CBID but this may not always be the case. He suggested two ideas with potential to make these partnerships more equitable and more effective at promoting inclusion of persons with disabilities. The first is to ensure the Northern partner implements a process of understanding others with mutuality, respect and humility. Cleaver called this 'Asymmetrical reciprocity'. The second is the practice in which a person of privilege seeks to operate in solidarity with a marginalized group of people throughintentionaland active resistance to moments when one's privilege forces others to the margin – described as 'Allyship'.

Mr. Daisuke Sagiya of the Department for Social Development (DSD)of South Africa reported that the Department is collaborating at many different levels in South Africa, helping to establish self help groups and peer counselling, carrying out disability equality training and networking with government agencies, federations and DPOs in South Africa as well as neighbouring countries of Lesotho, Swaziland, Botswana, Namibia, Zimbabwe and Mozambique. The DSD is collaborating with The Japan International



Cooperation Agency (JICA) on good practices in CBID, which are being documented as part of a guideline to be shared with the other countries in the region.

Many of the questions relating to this subtheme focused on the participation and involvement of people with disabilities in various sectors. It was felt that people with disabilities should be encouraged to unite and promote their own self-help group as a vehicle to their inclusion in the development agenda.

#### Sustainable Development Goals and CBR: country progress

Simon Munde of FEDOMA reported that FEDOMA is the umbrella Federation of 11 disability organizations in Malawi (FEDOMA), committed to ensure that the domestication of the SDGs in Malawi should not leave people with disabilities behind. It has used the power of its DPO network and the existence of a national advocacy committee within it to advocate for people with disabilities as well as bringing together allies from mainstream civil society to support the "leave no person with disability behind" agenda. Malawi committed to implement the SDGs through the Malawi Growth and Development Strategy. Taking advantage of the expiry of the MGDS II, the DPO movement developed a strategy that would make the successor development blueprint disability inclusive. FEDOMA's advocacy efforts have included media campaigns, and awareness raising initiatives including the use of the commemoration

of the International Day of Persons with Disabilities.

Doreen Kauma looked at the level to which SDG Goal 1 – No poverty and SDG Goal 10 Reduced Inequalities are being met for people who are deaf in Uganda, through a case study of access to the special grant and other programmes. The findings showed that only 28% of deaf people had accessed the grant and main inhibitors were communication barriers, discrimination by the grants committee and ignorance in knowledge of the grant.

In Zambia, Thomas Mtonga, Kalisto Kalimaposo and Gift Lungu of the University of Zambia, investigated the levels of awareness on SDGs by DPOs and assessed the extent to which DPOs and people with disabilities were included in the planning and implementation process of SDGs. The study revealed that while DPOs were aware of the SDGs, only about 20% of the disabled respondents showed clear knowledge of their content, and they were not involved in their planning or implementation. 82% of respondents were not aware of domestication efforts relating to the SDGs. Mtonga asserted that: "The Sustainable Development Goals cannot be considered a success unless they are met for everyone - people with disabilities included." One respondent in their research said: "The problem of Zambia is not the lack of legal provisions but the absence of committed political will to reinforce the already provided legislation".

Uta Prehl of Humanity and Inclusion (HI) reported that to contribute to Goal 3 of the SDGs: Ensure healthy lives and promote wellbeing for all at all ages, HI has developed a tool called the 'Blue Box' to support early childhood development for children from 0-3 years. The Blue Box aims at promoting child development for children at risk of developing an impairment (such as those with acute malnutrition, a low birth rate, or who are institutionalized) or who already have an impairment. The tool is currently being tested in several countries.

Discussions around this topic applauded that the SDGs made specific mention of disability unlike the Millennium Development Goals (MDGs) that preceded them. The SDGs were seen by many delegates to offer a great opportunity for CBID workers to advocate for ensuring that the rights and needs of people with disabilities are considered as an integral component of SDG initiatives.

# CBR Africa Network AGM and elections



An important activity of each CBR Africa Conference is the CAN Annual General Meeting (AGM). The core AGM activities for CAN were carried out including reports from the Chair and the Treasurer. The election of new Executive Committee members was also held. Elie Bagbila from Burkina Faso retired after two terms in office, and was thanked for his significant input and commitment to CAN. It was announced that the two members to remain on the EC for continuity in line with the Constitution would be:

- Musonda Siame from Zambia (Chair)
- Pascal Ahidjo from Cameroon (Secretary)

The treasurer Carolyne Maholo from Uganda will also remain.

### New members were appointed as follows:

- Nabil Ezzat Khalil from Egypt Member
- Ann Ojugo Obehi from Nigeria Member
- Therese Dibassiwena Adjayi from Togo Vice Chairperson

In addition, Gideon Muga from Kenya (member) was reappointed for East Africa.



In line with CAN's Constitution the members will serve the organization until the next Conference in 2022.

#### **Closing ceremony**

The CAN Chairperson, Musonda Siame, remarked on the success of the conference that had drawn stakeholders from government ministries, civil society organizations, academia and other organisations. He said that learning from the conference should be implemented and not just end at the conference.

The Minister of Community Development and Social Services, the Honorable Emerine Kabanshi reiterated that the conference had been a success. She thanked the President of Zambia, His Excellency Mr. Edgar Chagwa Lungu for having created time to be with the participants at the conference. She also thanked the First Lady, Mrs. Esther Lungu for also having come to grace the conference. It showed they had commitment to issues pertaining to persons with disabilities. She reinforced the message that the closing of the conference was just the beginning of implementing CBID.

Standing in for the Vice President of Zambia, The Honorable Minister of Health, Dr Chitalu Chilufya, made the official closing. He said the Vice President regarded disability as an issue that needed to be addressed urgently. Rehabilitation should be addressed as a fundamental component in the continuum of care. Health provision does not just lie with the Ministry of Health; it is about prevention of diseases in the community, addressing a range of key issues such as good nutrition, and good sanitation. Income was key to health. That was why the Social Cash Transfer programme was scaled up and 15% of the beneficiaries are people with disabilities. There was need to ensure inclusive development was carried out and hence work had just begun. Participants were urged to translate into action everything they had learnt - leaving no one behind.

Moses Chanda gave the final vote of thanks. He thanked government for co-hosting the conference with CAN. It was a great achievement and he urged government workers to stop working in silos because there was a deliberate policy put in place by government to work in clusters to achieve more.

### **Field visits**

On the final day of the conference delegates were invited to make field visits to different sites in Lusaka. In total, 113 of the delegates participated and the most popular venue visited by 36 participants was to CBR sites including the Library for the Blind, visiting families benefitting from social cash transfers, BEITCURE and the Sani Foundation. Other venues included the National Museum and the Presidential Burial site.

## **Conference resolutions**

- 1. The new constitution of CAN, which was written in 2016 to conform to Uganda Revenue Authority requirements and to move away from registration as a limited company, should be adopted.
- 2. People with disabilities and their organisations should be involved in planning, implementation and evaluation of government programmes at all levels.
- 3.Efforts should be taken to ensure participation of people with disabilities in the family and all sectors of the community.
- 4. There should be economic empowerment of people with disabilities as a contribution to community based inclusive development through Self Help Groups.
- 5. The education and training of rehabilitation personnel should be carried out in Africa using standardized curricula to facilitate effective community based inclusive development.
- 6.Countries in Africa should move away from CBR to CBID as the latter will be more effective with guarantees of capacity development and addressing funding gaps.
- 7.Community based rehabilitation / community based inclusive development practitioners should involve people with disabilities in all decisions that concern them.
- 8. In all African countries, all policy documents should be made available in accessible formats for all people with disabilities for effective awareness creation and advocacy.

- 9.Action research should be promoted to provide empirical evidence on the effectiveness of community based rehabilitation intentions for effective development initiatives.
- 10. There is urgent need for the domestication of The African Charter and Protocol on Disability, which is Africa's own context policy.
- 11. Data on gender and disability should be disaggregated for better profiling of people with disabilities for effective service provision.
- 12. Working relations/partnerships should be built among CSOs, DPOs and governments through sharing of responsibilities to reduce vulnerability of people with disabilities during service delivery.
- 13. Disability Focal Point Persons (FPPs) must be senior government officials who fully understand their role and are capable of taking forward issues pertaining to persons with disabilities.
- 14. Advocacy by DPOs should focus on existing legal systems backed by relevant Statutory Instruments.