2nd CBR World Congress
26 – 29 September 2016
Kuala Lumpur, Malaysia

CBR - Empowering and Enabling:
Community actions towards human rights and sustainable development through CBR
1  Foreword by the President of the CBR Global Network

We arrived in Kuala Lumpur for the 2nd CBR World Congress full of enthusiasm and expectations. I think I can speak for all of us when I say we were looking forward to sharing experiences, reflecting on achievements, and exploring the future of community-based inclusive development.

I am more than gratified that those high expectations have been fulfilled. This was largely due to some excellent Congress presentations and a series of dynamic interactive workshops. The highlight for me was the exchange of grassroots experience between practitioners from across the regions, and those presentations that stretched our thinking and took us to new conceptual places.

In the true spirit of CBR, we worked collaboratively, the diversity of our experience strengthening our thinking. We thought long and hard about the challenges we have to face during the next five years and beyond. Because this was, first and foremost, a forward-looking Congress packed with challenge, creativity and confidence. Our deliberations were of course rooted in an understanding of the essential role of people with disabilities, their families and community, and in our fundamental belief in the practice of interdependence and mutual support.

This was reassuring in a world where community and interdependence are being fragmented and destroyed by rapid urbanization and market fundamentalism, both of which favour individuality over collectivity, and the wealthy over the poor. Every time a public resource, such as water, is privatized or land is appropriated in the name of development, it is the poor who suffer most from rising prices or loss of livelihoods. These issues have to be part of any Community-based Inclusive Development (CBID) project. The synthesis that emerged from our Congress was that, despite this reality of growing inequality, the phenomenon of collaborative working is still the best way to harmonize human rights with development.

In my closing address, I said that we have the chance to strengthen our movement if we embrace the struggles of others just as we wish them to embrace...
ours. The issues that affect other groups affect us too. The issues that affect women, for example, affect disabled women too, but more so. The issues that confront trans people confront trans disabled people too, but more so. And the issues that impact on tribal people, impact on disabled tribal people even more so. People with disabilities have a more complex identity than just being disabled. We have to integrate this fact into our work.

The future for us all lies in solidarity and not fragmentation or exclusivity in the name of inclusion. This is the challenge for us all – for our philosophy and our practice, for theorists and practitioners, for those who were at the Congress and those who were not. Our path forward to 2020 is clear. Community-based inclusive development can only succeed with strong grassroots organisation, solidarity between struggles, sound methodology and sustainable practice. This is our challenge for the next five years.

As the president of the CBR Global Network it is my pleasure to present to you the 2nd CBR World Congress report. I am already looking forward with anticipation to the 3rd CBR World Congress in 2020.

Balakrishna Venkatesh (Venky)

Photographs © CBR Global Network 2016
Report published: August 2017
Report written by Judith van der Veen, World Health Organisation
Edited by ASPS, Alison&SimonPartnership

Front cover photo:
Her Excellency Dato Rohani binti Abdul Karim, Minister of Women, Family & Community Development, Malaysia with Paralympic medal winners at the CBR Global Network 2nd World Congress in September 2016
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# 2 Abbreviations

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<th>Full Form</th>
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<tr>
<td>APCD</td>
<td>Asia-Pacific Development Centre on Disability</td>
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<td>BISPA</td>
<td>Bislig Special Persons Association, Philippines</td>
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<td>CAN</td>
<td>Community-based Rehabilitation (CBR) Africa Network</td>
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<td>CBID</td>
<td>Community-based Inclusive Development</td>
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<td>CBR</td>
<td>Community-based Rehabilitation</td>
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<td>CGN</td>
<td>CBR Global Network</td>
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<td>CNM</td>
<td>CBR Network Malaysia</td>
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<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
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<td>DADO</td>
<td>District Agricultural Development Office, Malawi</td>
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<td>DDS</td>
<td>Dubai Disability Strategy</td>
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<td>DEM</td>
<td>District Education Management, Malawi</td>
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<td>DID</td>
<td>Disability Inclusive Development</td>
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<td>DPO</td>
<td>Disabled Peoples Organization</td>
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<td>DRR</td>
<td>Disaster Risk Reduction</td>
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<td>FEDOMA</td>
<td>Federation of Disability Organization in Malawi</td>
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<td>GATE</td>
<td>Global Assistive Health Technology Cooperation</td>
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<td>ICT</td>
<td>Information and Communications Technology</td>
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<td>IDA</td>
<td>International Disability Alliance</td>
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<td>IDDC</td>
<td>International Disability and Development Consortium</td>
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<td>IDP</td>
<td>Internally Displaced Person</td>
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<td>LPFI</td>
<td>Loving Presence Foundation Incorporated</td>
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<td>NGO</td>
<td>Non-Governmental Organization</td>
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<td>MACOHA</td>
<td>Malawi Council for the Handicapped</td>
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<td>MCR</td>
<td>Malaysian Council of Rehabilitation</td>
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<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
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<td>PIE</td>
<td>Participation Impact Evaluation</td>
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<td>PSG</td>
<td>Parents’ Support Group</td>
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<td>SHG</td>
<td>Self-Help Group</td>
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<td>SDG</td>
<td>Sustainable Development Goals</td>
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<td>TOT</td>
<td>Training of Trainers</td>
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<td>UAE</td>
<td>United Arab Emirates</td>
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<td>UNCRPD</td>
<td>United Nation’s Convention on the Rights of Persons with Disabilities</td>
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<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<td>WASH</td>
<td>Water, Sanitation and Health</td>
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3 Executive summary

The theme of the 2nd World Congress was CBR - Empowering and enabling: community actions towards human rights and sustainable development through CBR.

Almost 1,000 people from 69 countries participated in the Congress, which was hosted by the Malaysian Government, CBR Global Network (CGN), CBR Network Malaysia (CNM), Malaysian Council of Rehabilitation (MCR) and the World Health Organization (WHO). Its stated aims were to: improve practice among CBR practitioners, and hence improve the quality of life for those who are living with disabilities; to increase family and community awareness of the care and health needs of those with disabilities; and to enhance and promote strategies that integrate whole communities regardless of disabilities.

Presenters during the main plenary sessions, the workshops, and the breakout meetings, were from 44 countries with a majority from low and middle-income countries. This highlights the fact that CBR is primarily a grassroots movement active in the global south, and implemented by thousands of people working and cooperating on CBR issues.

On the first day of Congress, there were pre-Congress workshops on the joint IDA - IDDC Bridge project, disaster risk reduction (DRR) in CBR, and on appropriate wheelchair provision.

In his keynote address, Chris Underhill, Founder and President of Basic Needs, deliberated on the framework needed to ensure that people with disabilities make their contributions to society as citizens of their countries and of the world. It was recognised by all during the Congress that the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is the most valuable tool in the policy framework for guiding CBR. Another important tool is the Sustainable Development Goals (SDGs), which are now approaching the end of their first year of operation. It was acknowledged that, at present, few countries possess the capacity needed to ensure their implementation. Various speakers highlighted the unique role CBR can play as a bottom-up strategy for disability-inclusive development in the community.

As stated by the CGN President, Balakrishna Venkatesh (Venky), the deliberations during the Congress were ‘rooted in an understanding of the essential role of people with disabilities, their families and community, and in our fundamental belief in the practice of interdependence and mutual support…. that despite the reality of growing inequality, the phenomenon of collaborative working is still the best way to harmonize human rights with development’. He went further in his remarks to draw links between the struggles of women, girls, boys and men with disabilities and the struggles of other marginalized people, as well drawing attention to the intersectional nature of the human experience.

Thereafter, each day of the Congress started with a plenary session, followed by parallel sessions, and, in the afternoons, an interactive session where the outcomes of a survey on CBR were used to facilitate group discussions on the current status of CBR, and its future.

Presentations and discussions took place on the themes of sustainability, the CBR workforce, capacity development, CBR stakeholders, CBR in practice, monitoring and evaluation of CBR, and
research. The CBR World Congress is the only global opportunity to exchange grassroots experience and learning from across the world of CBR. There was a great variety of experiences and contexts and of practice too, such as the lack of services at community level, the stronger involvement of CBR in service delivery and in many cases helping to strengthening these services and holding local systems to account for inclusion.

The diversity of people with disabilities involved in CBR has expanded, and while experiences described at Congress revealed that there is a long way to go in terms of both diversity and capacity to support people, they also demonstrated that we are seeing progress e.g. in the inclusion of people with psycho-social disabilities and people with intellectual disabilities, and greater levels of participation in planning, implementing, and the monitoring and evaluation of CBR.

The level of government engagement in CBR varies, ranging from none to partial to full local government ownership, to national CBR programmes. However, a clear growth in government engagement can be seen between the 1st and 2nd CBR Congresses (2012 and 2016). There remains a need to create greater awareness about CBR and its potential at local, national and international levels.

The 2nd World Congress for the first time included interactive sessions which enabled participants to contribute actively to the Congress proceedings through facilitated reflection and dialogue about a set of issues which contributed to the Congress recommendations on the way forward for CBR. The introduction of these sessions at the World Congress was noted as a highlight in feedback from Congress participants. Participants appreciated the opportunity to discuss CBR topics with people from different backgrounds and from different parts of the world.

Alarcos Cieza, Coordinator of the Disability and Rehabilitation, Blindness and Deafness Prevention Unit of the WHO, concluded by saying ‘Do not be afraid to lose the R: Rehabilitation should be seen as part of universal health care.’

Balakrishna Venkatesh (Venky) noted that ‘Our path forward to 2020 is clear. We can only succeed with strong grassroots organisations, solidarity between struggles, sound methodology and sustainable practice. This is our challenge for the next five years’.

This report – a precis of Congress proceedings – will introduce the Congress and its structure, and then describe the discussions and findings of the Pre-Congress workshops, the Plenary, Parallel, and Interactive sessions. It concludes with the Kuala Lumpur Declaration, the valedictory conclusion of the Congress, which is a call for continued practice and advocacy, and is a major milestone in making the voice of the CBR Global Network heard.
4  The 2\textsuperscript{nd} CBR World Congress

The 2\textsuperscript{nd} CBR World Congress took place at the Berjaya Times Square Hotel, in Kuala Lumpur, Malaysia, between 23th and 26th September 2016. The Congress was hosted by the Malaysian Government, the CBR Global Network (CGN), the CBR Network Malaysia (CNM), the Malaysian Council of Rehabilitation (MCR) and the World Health Organization (WHO). A total of 942 participants from around the world attended representing 69 countries. It was a large and diverse gathering of CBR people including practitioners, people with disabilities, development agencies, government representatives and academics.

The objectives of the Congress were:

1) To create an international platform for taking stock of CBR around the world, and for engaging in deliberations to ensure its relevance in a post-2016 world in which the human rights and development agendas are closely linked.

2) To recommend effective ways and means of building the capacity of all stakeholders to use CBR as a strategy for inclusive development.

3) To facilitate dialogue among CBR practitioners, DPOs, civil society, government and academia around critical issues in CBR.

5  Structure of the Congress

The Congress used a variety of types of session:

Pre-Congress workshops

Three pre–Congress workshops took place one day before of the start of the Congress. These Pre-Congress workshops covered three topics:

1) the BRIDGE project, training DPO leaders in bridging the human rights and development agendas.

2) Disaster risk reduction and CBR.

3) Appropriate wheelchair service provision: progress, challenges and resources.

Plenary sessions

Each day started with a plenary session of one and a half hours in which four papers were presented on a particular topic. The topics were:

Day 1:  Country perspectives on the sustainability of CBR.

Day 2:  Regional perspectives on CBR.

Day 3:  Innovation and evidence.
Parallel sessions

The Parallel sessions took place in seven break-out rooms.

A total of 104 papers were presented under the themes:

1. Sustainability of CBR
2. CBR workforce and capacity development
3. CBR stakeholders
4. CBR in practice
5. Monitoring and evaluation
6. Research

Presentations were given by practitioners, people with disabilities, government representatives, civil society organizations, and academics.

The Congress had a broad mixture of presenters from 44 countries with a variety of backgrounds, with the majority of the presenters coming from the global south.

The regional breakdown of presenters was as follows:

Asia/Pacific (14): Bangladesh, China, India, Indonesia, Laos, Malaysia, Mongolia, Myanmar, Nepal, Philippines, Pacific Islands, Sri Lanka, Thailand and Tajikistan.


Latin America and the Caribbean (6): Bolivia, Colombia, St Kitts and Nevis, Cuba, Ecuador, Honduras and Nicaragua.


Other countries (6): Australia, Canada, Germany, Japan, United Kingdom and UAE (Dubai).

Interactive sessions

The purpose of the Interactive sessions was to enable participants to contribute actively to the Congress proceedings through facilitated reflection and dialogue about key issues, leading to Congress recommendations on the way forward for CBR.

Each of the three sessions started with a summary of the outcomes of the PULSE survey and focus group discussions which took place around the world with CBR practitioners and stakeholders prior to the Congress. Each day had a theme linked to the day’s presentations. The first day’s theme was Sustainability and CBR structures. The second day’s theme was Workforce and Professional Development, and the third day’s theme was The Way Forward for CBR.

The sessions were lively with wide-ranging discussions. The introduction of these Interactive sessions at the World Congress was noted as a highlight of the Congress in feedback from participants. Participants appreciated the opportunity to debate and discuss CBR topics with others from different backgrounds and different parts of the world. The sessions concluded with a set of key messages which were presented back to a plenary session at the end of each day.
Poster Presentations

Thirteen posters were displayed in the foyer. People could pass by during lunchtime and coffee breaks. Presenters were on hand to explain, and answer questions.

Some of the topics presented were:

- Disability awareness toolkits.
- UNCRPD and the Incheon framework in action.
- Sustainability and community-based inclusive development programmes.
- Early identification and screening to identify children with developmental disabilities.
- Inclusive health, rehabilitation and (inclusive) education examples.

6 Pre-Congress workshops

Three practical workshops took place the day before the official start of the Congress.

Workshop 1: The BRIDGE project

This workshop was jointly organised by the International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC). Its objective was to introduce the BRIDGE training initiative about the Convention on Rights of Persons with Disabilities (CRPD) and the Sustainable Development Goals (SDGs) to CBR and Disabled Peoples’ Organisations (DPOs) stakeholders. It initiated a dialogue on capacity development requirements for CRPD-compliant enforcement of the SDGs for people with disabilities, and sought to identify potential opportunities to engage in BRIDGE regional dynamics.

The workshop was attended by 70 participants. The workshop consisted of interactive sessions exploring understanding and ideas around CRPD principles and inclusive programming, and how training contexts can be made inclusive of all types of disabilities.

The BRIDGE training aspires to build a critical mass of leaders with disabilities who are able to advocate for inclusion and human rights for all people with disabilities. Since 2015, the training has been piloted in five regions using an integrated approach, bridging the gap in advocacy between human rights and inclusive development. It aims for the full and effective participation of all in environments that may be resource-constrained, and/or suffer poor governance, and competing agendas.

Participants expressed interest in being more involved and requested information about next steps. They also requested information about the BRIDGE training in soft copy and enquired if BRIDGE trainers would be willing to support the development of this type of training at national level.

More information can be found on the website:
http://www.internationaldisabilityalliance.org/content/bridge-capacity-building
Workshop 2: Disaster Risk Reduction (DRR) and CBR

The workshop was designed to be participatory, drawing on participants’ experience of including DRR in CBR implementation. Its objective was to define recommendations on how to include disability-inclusive DRR in CBR. A total of 40 participants attended including representatives from international and non-governmental organizations, regional networks, and members of DPOs. The workshop combined presentations and working groups organized in four sessions:

Session 1: The context of disability and DRR.
Session 2: Learning about the Centre for Disability and Development’s experience on community-based inclusive DRR in Bangladesh.
Session 3: Learning from the Philippine Coordinating Centre for Inclusive Development’s experience on community-based inclusive DRR in the Philippines.
Session 4: Interactive consultation - seizing opportunities for implementing DRR in CBR programmes.

The key learnings were that disability-inclusive DRR should be part of any community-based development programme in order to ensure the protection and safety of people with disabilities and their whole community. DRR activities can support the strengthening of groups of people with disabilities and the identification of people with disabilities as leaders. DRR can contribute to the resilience of a community through the protection of lives and assets while decreasing the impact of disasters and enhancing quick recovery. CBR could be used to ensure that DRR national strategies are translated into local frameworks ensuring the needs of people with disabilities are taken into account.

Workshop 3: Appropriate Wheelchair Service Provision - progress, challenges and resources

The International Society of Wheelchair Professionals (ISWP) hosted a pre-Congress Wheelchair Service Provision Workshop. The objective was to improve the participants’ understanding of the benefits of appropriate wheelchair services, and how CBR can improve outcomes for wheelchair users. The half-day workshop was attended by 60 representatives from 20 countries. Participants included wheelchair users, rehabilitation professionals, and representatives of NGOs, DPOs, and government bodies. The workshop involved sharing the experience of a wheelchair user who is also a peer supporter. The presenter talked about the provision of wheelchairs which are appropriate to the person and the context, and about mobility as a human right. During the workshop, the WHO Wheelchair Guidelines were outlined and it was emphasized that wheelchairs must be provided through an eight-step service system approach by personnel with the relevant level of training. CBR plays a crucial role within this eight-step service to ensure wheelchair services are accessible and appropriate. Two discussion sessions dealt with questions on four topics: products, services, training and inclusion. Participants discussed challenges in their country contexts and worked together to identify potential solutions. The workshop was an important step in raising awareness among key stakeholders of the needs of wheelchair users, and their potential role within wheelchair provision systems.
7 Opening ceremony

The opening ceremony for the 2nd CBR World Congress started with the Malaysian national anthem and a recitation of the Islamic supplication, the Doa.

The musical presentation at the opening ceremony was warmly received

Balakrishna Venkatesh (Venky) - CBR Global Network President

The welcoming speech was given by the President of the CBR Global Network, Balakrishna Venkatesh (Venky). He highlighted that people with disabilities are part of the mainstream and need to involve themselves in different areas: ‘Inclusion is often seen as a one-way street but if we really want to be included what are we doing to be included? As long as we don’t engage in matters that concern the common people we shall always remain excluded’.

Alarcos Cieza – World Health Organization

In her speech, Alarcos Cieza questioned where CBR sits in different countries’ structures, and who holds responsibility for it. She asked participants to consider if they are promoting community rehabilitation or inclusive development: ‘You need to know what you are deciding. A budget for rehabilitation services at community level or a budget for CBID? Where should the CBR budget sit – at the Ministry of Health or with the disability council under the Ministry of Social Affairs?’

She stressed that CBR contributes to global agendas such as the SDGs, so that people with disability are not left behind and participate in society on an equal basis to others. It does this using a bottom-up approach. This is fundamental because top-down agendas like the SDGs need bottom-up strategies like CBR to be successful. She stated that she believes that this potential of CBR is not fully recognised by stakeholders, ministries, funding bodies, and decision makers in the community, and that some stakeholders might even be sceptical about CBR. She explained that there is a lack of clarity in fundamental issues regarding CBR and suggested that we cannot continue without clarity. She reminded Congress that the stakeholders deserve answers, and without clarity they will not be able to develop CBR to its full potential. Questions that need answering are about sustainability, governance, workforce and what makes CBR distinctive from rehabilitation in the community and what is the evidence for CBR success?

She stated that she would consider this Congress a success if:
1. All participants come to a recognition that there is an urgent need to address together the challenge of sustainability of CBR.
2. The dialogue about a way forward continues.

Her Excellency Dato Rohani Binti Abdul Karim, Minister of Women, Family and Community Development, Malaysia formally opened the conference:

‘I take this opportunity to extend a warm welcome to everyone and it is a great pleasure for the Malaysian Government to co-host this Congress together with the CBR Network Malaysia and the Malaysian Council for Rehabilitation, as it demonstrates a synergistic strategic partnership between the government and civil society for the best interest of persons with disability. In Malaysia, currently there are 527 CBR centres and many programs are organised around the CBR matrix such as health, education, livelihood, social and empowerment. Malaysia has ratified the Convention on the Rights of Persons with Disabilities on 19 July 2010, affirming the human rights of persons with disabilities. The government is fully committed to the welfare and well-being of its disabled citizens and will continue to give the necessary support on ensuring that the CBR programmes continue to provide a meaningful and beneficial service, not only for people with disability but for the community as a whole.

Furthermore, I would like to take this opportunity to congratulate all the Malaysian Paralympians who won medals at the Paralympic Games in Rio in 2016. We have invited the medal winners and to honour their achievements in sport, the Ministry of Women, Family and Community Development is very grateful to name our welfare institutions after these great Paralympic athletes.

With that, I wish all of you, especially the delegates, a fruitful discussion and an enjoyable stay in Malaysia. I now have the pleasure in declaring open the 2nd CBR World Congress. ‘Wabillahitaufik Walhidayah Wasallam Mualaikum W.B.T.’
Keynote address
Chris Underhill, MBE - Founder and President of Basic Needs

A framework for progress

Chris Underhill started by saying that this Congress is all about the future. ‘The aspiration to empower which lies at the heart of the Congress is just and lofty, and asserts that through their own contribution disabled people are assets both to their local communities as well as to their nation.’

He said: ‘In 1985 I founded Action on Disability and Development, ADD International. Subsequently we founded ADD India which our Congress President, Balakrishna Venkatesh, directed with distinction for a number of years. In 2000, I founded Basic Needs (new initiatives in mental health and development) and recently have co-founded mhNOW focusing on the mental health systems of cities both North and South.

We have established that this Congress is about development and how persons with disabilities make their contribution to society as citizens of their country and world. What then is the framework that a citizen, in this case a citizen with a disability, must work within? What then are the barriers that these citizens face?

As part of the framework the person with a disability can now rely upon several important tools. The most important of which is the UN Convention on Rights of Persons with Disabilities, with the second tool being the Sustainable Development Goals, which are now coming up to their first year of operation.

If we were to draw an imaginary triangle in the air right now at one tip you have the CRPD and on the second tip you have the SDGs. What then do we have on that third tip? The SDGs and CRPD are both top down instruments, fought for at the highest level. What we are missing is a bottom up approach and for this we turn to persons with disabilities, organised in alliance, both within their own community and between communities. This is a bottom up approach and so the top down portions of our triangle need to be balanced by a ‘bottom up’ approach, where the citizen can organise and can be heard. So, you have (i) CRPD, (ii) SDGs, (iii) the community - with persons with disabilities, as full citizens at the centre of a community alliance. This bottom up mechanism is known as Community-based Inclusive Development or CBID.

Persons with disabilities have a right to expect good and effective treatment both for their impairments and their chronic medical conditions so that they can act as full citizens. So, the technical medical contribution is important and we should celebrate the skills that all too few specialists provide in community settings. However, to be a full citizen, the person with disability has to also be part of a political project that enables and empowers her/him to take their place at the centre of the community. This rights-based approach, this inclusive approach, requires funding, requires backing and requires training.
It is at this point in the development of our framework that we see the possibility of a sustainable future. Vulnerable people (for example persons with disabilities and mentally ill people) know what it is to feel oppressed, as do their family members and carers, the all too important carers who we also celebrate today. Yet, as we stand at the brink of a new possibility, we also see, and we also feel, the possibility that these very victories will be snatched from our hands. The old enemy of stigma and prejudice has a new face that affects all the citizens of a community: namely inequality. As Warren Buffet said: ‘We have been fighting a class war, for the last 20 years, and my class has won.’

What does this mean for us all? Not only does this mean that poor people will have less resources to manage with, but those who already started with little will find it even harder to accumulate...and to organise. In fact, it is in the recognition of this new threat that there comes a possible way forwards...for it is only if the whole community recognises this inequality that each part of it can make progress, be it for women, disabled peoples, farmers, factory workers, and so on. Together we stand, divided we fall.

As we think about the future of CBR at this Congress, we should not be confused. Be brave. See things for what they are. On the one hand, we need good rehabilitation and medical services in the community. On the other hand, we need inclusive community development, a spider’s web of alliances and of networks to ensure that persons with disabilities can achieve their full rights as a person and that all members of a community will not be left behind.’
8 Plenary sessions – main messages

Plenary day one: Country Perspectives on the Sustainability of CBR

Chairs: Setakari Mcanawi, Dr. Gerald Gwinji, Sandra Willis, Peter M. G. Ngomwa, Paul Edward Muego

This Plenary session presented the development and sustainability of CBR. This contrasted a high-income country with a low and lower-middle income country.

‘A City for Everyone’ was presented by Sandra Willis from Dubai, United Arab Emirates (UAE). The leadership in Dubai wants to ensure that it is transformed into a disability-friendly city by 2020, and, to this end, a comprehensive strategy was developed in 2015. The ‘Dubai Disability Strategy 2020’ seeks to empower people with disability to enjoy their basic rights by ensuring social justice, equity, and protection via five main pillars: inclusive education, inclusive healthcare, social protection, inclusive employment and universal accessibility. The strategy is implemented through five multi-sectoral, multi-representation task forces for rehabilitation, accessibility, social protection, inclusive education and inclusive employment.

Peter Ngomwa from Malawi explained that the National Policy on Equalization of Opportunities for Persons with Disabilities (2006) endorsed CBR as its implementation strategy. The Malawi Council for the Handicapped (MACOHA) coordinates the national CBR programme through the Ministry of Disability and Elderly Affairs in Malawi. CBR planning is done at district level and is then submitted to central government for funding. Planning is bottom-up. District CBR Coordinating Committees report to the District Development Committee. The Federation of Disability Organizations in Malawi (FEDOMA) represents people with disabilities at all levels. The Local Government Act provides for this arrangement under provisions for interest groups. A new CBR strategy was recently developed. The objectives of CBR are to make sure disability is mainstreamed into sectoral plans, programmes and services at local government level, and this includes joint planning, implementation, and reviewing plans and budgets.

Joselito Buenaflor presented the development of CBR in Bislig city in the Philippines. It was initially started by the NGO Loving Presence Foundation Incorporated (LPFI), in collaboration with Bislig City government, through the Social Welfare and Development Office. It supports one volunteer in each village and the establishing of the Bislig Special Persons Association (BISPA) within the 24 villages. CBR is a collaborative activity and is implemented by various partners. Among the partner agencies are NGOs, rehabilitation facilities and hospitals. One of the outcomes of their work was the establishment and funding of the Persons with Disabilities Affairs Office (PDAO) in Bislig. 1% of the city’s annual budget is intended for persons with disabilities and senior citizens. Hence, programmes and services are funded appropriately, which ensures the programme’s sustainability. Another impact has been the empowerment of persons with disabilities and their representation in local bodies such as the City Development Council. Their voices are considered in the planning process of the city government.
and recognized as an important part of the community. The important lesson that a competent NGO as an enabler is vital when initiating CBR.

**Plenary day two: Regional Perspectives on CBR**


This plenary showcased the development of CBR in four regions around the world - Africa, the Americas, Asia Pacific and the Arab Region. The presentations showed common points between CBR programmes as well as the diversity of local contexts.

The Africa region presenter was Alick Nyirenda from Zambia. Africa has a well-established CBR network that was founded in 2001. Key developments governments have now adopted and ratified the UNCRPD. The disability movement is strengthening in Africa especially at national levels, where they have moved from advocacy to a more collaborative way of working with government. As a result, efforts are on the way to realigning policies and legislation, and implementation plans are being developed which are beginning to be beneficial. Decentralized forms of government have helped to improve the participation of people with disability and service delivery in local councils and communities. It is recommended that ‘African governments should ‘ring-fence’ funding for multi-sector and multi-disciplinary implementation of CBR, DPOs should actively budget-track allocated resources’. Many challenges remain, such as pervasive poverty and the non-availability of rehabilitation services.

The Asia Pacific region presenter was Andrea Vogt who works in Tajikistan. She stated that it is time to take stock of our situation, and that CBR, as well as each of us, can contribute to making the UNCRPD and development agendas a reality and truly ‘leave no one behind’. She was hopeful that during and after the Congress we can say that CBR is a key strategy to achieve the SDGs and make them inclusive in more than words. Due to its bottom-up traditions, few CBR programmes have been scaled up systematically. ‘While we say and demand that our work is relevant to the big national and international agendas, the impact of CBR is still rarely empirically proven, and data is not always collected in a comprehensive and comparable way. CBR workers still lack recognition as a professional group and the absence of training, certification and accountability within health, social protection, education and community development systems and ministries’. CBR practitioners are far away from policy makers. She stated that cooperation between policy makers, marginalized groups and implementers is a must. She stressed the need to network on an ongoing basis and build bridges between those who are marginalized and policy makers.

The Americas region presenter was David Lopez from Nicaragua. He explained that in Ecuador, Bolivia and Cuba, CBR has been adopted by the respective governments, but in other countries it still depends on NGOs. In Ecuador, existing CBR projects are recognized and financed by the government, expanding its coverage from the local to the national ambit. In Bolivia, the government is training officials in the knowledge and application of the CBR strategy. In 2012, Nicaragua adopted a CBR strategy whereby it was defined as inclusive community-based development. What stands out in
Nicaragua is the broad leadership of people with disabilities in the implementation of CBR. It is intended to strengthen this process with the implementation of the new project. The government wants to institutionalize CBR as a pillar for sustainability and growth over time. Examples include strengthening processes of income generation and social and educational inclusion of people with disabilities. ‘It is intended to increase the sustainability of the projects by mainstreaming the disability issues into the programmes of municipal and departmental development’.

The Arab region presenter was Alaa Sebeh from Egypt. In this region, the medical model is still quite dominant in many countries. There are strong movements of people with disability but they are alienated from CBR and are relatively weak at community levels. CBR is still widely perceived as a low-cost and low-quality programme and NOT as a strategy (except in Palestine and Palestinian refugee camps). CBR programmes have limited coverage (small isolated islands), moving slowly from a traditional service delivery approach to inclusive development and empowerment of people with disabilities, but they rarely address poverty alleviation. However, some excellent pockets of good practices exist. In Jordan, the government (Higher Council of Disability) initiates most CBR programmes.

In Egypt, Jordan and Syria, CBR programmes are mainly initiated by NGOs who use professional staff, but despite the high quality of services, sustainability remains the main challenge. NGOs collaborate with government bodies but do not believe that governments have the capacity and means to lead CBR programmes. In other countries in the region, we find weakened structures due to conflict and wars, and they receive very little international support.

**Plenary day three: Innovation and Evidence**

Chairs: Azman Mohd Yusof, Chapal Khasnabis, Mary Wickenden, Rajaran Subbian & Naira Avetisyan.

The presentations highlighted that collaboration and partnership between stakeholders, and a whole government approach, leads to success. CBR human resource planning and development should be an essential part of the future strategic development of CBR.

Chapal Khasnabis from the WHO highlighted the need for assistive devices for people of all ages with all types of functional difficulties. Assistive products are now seen as a medical device. Only 10% of people in need of assistive devices have access to them. There is a large North – South divide. Many products are overpriced and the poor often receive low quality products. WHO is taking steps through its GATE project (Global Assistive Health Technology Cooperation) to make good-quality assistive products affordable and available. It developed a 25-item priority assistive products list. To provide the products, CBR can be the intermediary between the user and health and welfare services.

Mary Wickenden from University College, London, highlighted the need for an evidence-base and for the evaluation of CBR. She presented the PIE tools (Participation Impact Evaluation), a flexible approach to evaluate the impact of CBR and inclusive development programs, and to look at CBR as a structure. PIE results point to a structure including a core team that interacts with a network of strategic partners working together to bring about change in the lives of people with disabilities.

Rajaram Subbian from Basic Needs India gave a presentation about mental health and community development: The integration of people with psycho-social disabilities. Basic Needs is an organization that builds access to affordable treatment at community level. He pointed out that
there is a lack of availability of mental health services and when available only medical management is offered. Basic Needs supports people with psycho-social disabilities to develop sustainable life skills. It builds the capacity of stakeholders and carries out research. Working through an individual, a family or group, or by altering the situation, the behaviour can be changed.

The United Nations Children's Fund’s (UNICEF) contribution to CBR was presented by Naira Avetisyan. Guided by the Convention on the Rights of the Child (CRC) and UNCRPD, UNICEF’s mandate is to promote the rights and address the needs of children with disabilities in their first two decades of life. The aim is for their full inclusion in society both in development and in emergencies and humanitarian contexts. UNICEF programmes utilize a twin-track approach: while building internal capacity to provide inclusive services to children and adolescents with disabilities, they also invest in specific programmes and strategies to address their needs. ‘We could state that UNICEF’s work somehow contributes to CBR with its multi-sectoral disability-inclusive development approach.’
9  Highlights from the Parallel sessions

The highlights of the parallel sessions are presented under the Congress themes:

1. Sustainability of CBR
2. CBR stakeholders
3. CBR workforce and capacity development
4. Monitoring, evaluation and research
5. CBR in practice
6. Education & livelihoods

9.1. Sustainability of CBR

Chairs: Soumana Zamo, Siphokazi Gcaza Sompeta, Alaa Sebeh, Alick Nyirenda, Rajaram Subbian & Sulaiman Abd Mutalib
Rapporteurs: Hubert Seifert, Poly Varghese, Agnes Schaafsma, Heather Aldersey, Nathan Grills & Luc Pariot.

The various aspects of sustainability in CBR were described by presenters. The main aspects highlighted were CBR policy and strategy development, government ownership, development of CBR structures, networking and collaboration, CBR financing, and the participation and representation of people with disability and their families. Human resource development was also mentioned but will be highlighted under the workforce section.

9.1.1. UNCRPD, the SDGs and CBR

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was recognised by all as the guiding policy framework for CBR. A sizable percentage of countries have ratified the UNCRPD. It was acknowledged, however, that at present few countries possess the capacity needed to ensure its implementation. Presenters described the situation of people with disabilities in their country. It was highlighted that they experience higher rates of poverty, lower educational achievements, poorer health outcomes, less legal protection, and less political and cultural participation than people without disabilities.

It was noted by presenters that many people are excluded from development because of their disability, gender, ethnicity, age, caste, and poverty. A presenter from Malawi stated, ‘What about inclusion, if the majority of the population live in abject poverty and have difficulty accessing social services?’ The effect of such exclusion is a disturbing and deepening inequality across the world. Many presenters stated the importance of the SDGs which were adopted in 2015 as a guide to
sustainable development for all. Development can be inclusive - and can reduce poverty - only if all groups of people contribute to and share the benefits of development and participate in decision-making. People with disabilities experience stigma and discrimination in all aspects of their daily life. Particular groups were identified as often experiencing multiple forms of abuse and exploitation, specifically women and children with disabilities, those with psycho-social disabilities, those with intellectual disabilities, as well as those affected by leprosy.

Countries are looking at ways to implement the UNCRPD and the SDGs. Various speakers highlighted the unique role CBR can play as a strategy for disability-inclusive development in the community. Disability is a human rights issue that affects all people. As a Madagascar presenter stated: ‘CBR provides a local answer to the implementation of the UNCRPD and the SDGs’.

Several presenters agreed that over the past 30 years CBR has changed from a strategy that offers rehabilitation services in the community to a community development model. It has moved from primarily targeting and supporting people with disabilities and their families to focussing on governance structures, disability-inclusive programming and service delivery. An Australian presentation stated that ‘CBR is now seen as a universal model and framework for a multi-sectoral community inclusive development approach’.

CBR is now established as a world-wide strategy and movement, based on inclusive community development principles. A presentation from Nicaragua defines it as a strategy that facilitates the ‘construction of inclusive communities in a more just society, where people with disability can actively participate in social, political, economic and cultural development through the implementation of community initiatives that eliminate the barriers in the environment that prevent full participation’.

It was noted that the CBR strategy was not well known and understood beyond the immediate stakeholders involved in CBR. In fact, the discussions highlighted that even among CBR practitioners it appeared that there is a lack of clarity and differences of opinion about what CBR is. There is a need to create greater awareness about CBR. A presentation from Ecuador, among others, recommended that CBR stakeholders need to create awareness about CBR among different government ministries and DPOs.

9.1.2. Governance structure at national level

It was realised that to make activities sustainable there needs to be improved collaboration with governments. Several presenters stated that governments as duty bearers need to play a greater role in the development and implementation of CBR. For programmes to be sustainable they need sound structures and systems with good governance and a capable workforce. In many countries, CBR was developed by NGOs as stand-alone projects. While these projects had a comprehensive approach, their impact has been restricted and they remained dependent on external financing.

It was recommended that each country develops a national CBR strategy policy and plan that guides the government and other sectors on their various implementation roles. Presenters from Malawi and Nepal suggested that such a policy and plan avoids duplication and fragmentation, and helps to ensure prudence on financial resources.

A representative from Egypt suggested that, at the national level, CBR should play a role in lobbying for inclusion of disability into laws and policies, and public budget reallocation for disability inclusive social and civil services such as health, education, livelihood, and social services.
Although CBR is a bottom-up approach it needs to be planned for at national level. A presenter from Tajikistan stated that functional cooperation between the policy and the implementation levels is key for scaling up CBR programmes to national levels.

9.1.2.1 Coordination mechanisms

Many countries have a disability coordination department in the ministry responsible for disability. In addition to this, several countries have set up ‘disability councils’ consisting of representatives of government departments, DPO and NGOs to coordinate inter-sectoral actions. Their role is to ensure that disability is included in the development of policies and programmes at national level as well as to monitor the implementation of the programmes. For example, the Mongolia government stated that the rights of people with disabilities will be ensured ‘through effective collaboration between the

Government of Mongolia and DPOs’.

9.1.3. Governance structure at local level

The presentations mainly discussed two different governance structures for CBR. One structure, that has as its focus mainstreaming disability, and a second that has its focus targeted support to individual people with disabilities and their families. The government is viewed as a duty bearer that needs to take responsibility for the development of CBR. Thailand encourages CBR programmes established under NGOs to engage with local governments as a major stakeholder and partner.

9.1.4. Governance structure with a focus on disability mainstreaming

A presenter from Niger explained that mainstreaming ‘contributes to the elimination of physical, communicative, and institutional barriers as well as those related to attitudes in order to facilitate inclusion of people with disability in community life’. Disability mainstreaming ensures that the needs of people with disability are included in any planned action, including legislation, policies and programs, in all areas and at all levels. The process must be inclusive of people with disabilities.

9.1.4.1 Coordination mechanisms

Programmes with a focus on mainstreaming disability have a structure under the department responsible for disability in which a disability coordinating unit was established. The unit facilitates community-based disability mainstreaming.

Several presenters stated that, although the unit is housed by one department under a ministry, it is of great importance that it works across sectors. Cross-ministry governance is essential for disability inclusion e.g. health, education, labour and social-cultural.

At local government level, a disability coordinating unit, housed and paid for by local government, was promoted as part of the CBR structure. This unit facilitates and technically supports disability mainstreaming. A clear set of functions for the unit needs to be developed. A presenter from Pakistan elaborated that the unit should be seen as the catalyst which gets actions started. The unit
develops synergies between DPOs, government, media, NGOs, and political leaders to contribute to sustainable community-based inclusive development. A CBR programme from Nepal reported that it works with the local DPOs and the wider disability movement to ensure the inclusion of people with disability at all levels in disability-inclusive development programme planning and implementation. This structure is recommended at both national and local levels.

The local government structure and system is strengthened through the establishment of a disability council or forum. It was advised that disability focal points are appointed in each local government department or ministry whose role is to facilitate disability inclusion and mainstreaming.

9.1.4.2 Functioning of Coordination Units

The role of CBR is to facilitate a commitment from local government for disability inclusion and to mainstream disability in government plans and programmes. In Madagascar, the government in collaboration with DPOs supported the development of a disability mainstreaming action plan to facilitate cross-sectoral mainstreaming. In Rwanda, cross-sectoral CBR coordination committees were put in place at local government level. In Indonesia, a disability council or coordination committee has regular coordination meetings to develop programmes and budgets to accommodate disability in the development agendas of a local government. Each department/sector, for example, health, education, livelihood and labour will articulate in their plans how they are purposefully including disability. A speaker from Bangladesh stated that ‘The basic concept inherent in the multi-sectoral and multi stakeholder approach to CBR is the decentralization of responsibility and resources, both human and financial, to community level organisations’.

9.1.5 Capacity development

It was found that an increasing number of governments are willing to include disability in policy, but lack the capacity to understand how to do this. A representative from Madagascar suggested that local authorities, church leaders, DPOs and professionals such as the CBR programme staff will need to acquire long-term technical expertise to meet the needs of people with disabilities and to facilitate mainstreaming and inclusion.

CBR programmes have started to facilitate capacity development. An example was given from Pakistan where training workshops on CBR and DID were organized for council staff as well as for DPOs. This included work sessions to design action plans for disability mainstreaming. Some programmes have established local training and resource centres for promoting disability-inclusive community development.

The importance of developing capacity among people with disabilities and their families was demonstrated in many presentations. It was noted that it is crucial that people with disabilities are at the centre of decision-making processes affecting their lives. This requires their inclusion at all development levels. CBR programmes support people with disabilities to build their capacity. In India, for example, leaders with disabilities were trained for advocacy at local to central level. People with disabilities also need technical understanding about local governance and how to mainstream disability. Increased knowledge and skills will enable people with disabilities to take up leadership roles in local governments. Examples, such as Egypt, were given of communities where people with disabilities have been elected into local elected committees.
9.1.6 Traditional leaders/local chiefs

Traditional leaders or chiefs have different names in different countries. They are often the first point of contact for a CBR programme when entering a community. Obtaining good collaboration helps to create awareness about the programme. Traditional leaders facilitate community mobilisation and the identification of people with disabilities. In Nigeria, for example, traditional leaders promote inclusion and participation, whilst in South Africa they contribute to CBR and involve the community through taking up roles as facilitators, advocates, consultants, and resource persons.

9.1.7 CBR resource centres

A system presented by several speakers was the development of a rehabilitation or disability resource centre in the local community. The focus is to support individual people with disabilities to get access to information and services. For example, in Myanmar the centre offers services to address the varied needs of people with disabilities, ranging from rehabilitation, provision of assistive devices, care-givers training, advocacy and livelihood support including skills training. The programme is implemented and funded by local governments and supported by civil society organizations.

9.1.7.1 Function of resource centres

The CBR resource centre offers a variety of services and it is based in the local community. People can come for information and services. It has a main centre at district/local government level but might have smaller units at village level.

Many programmes offer rehabilitation services. Several presentations showed that there is a lack of rehabilitation services in various countries. It was also found that the majority of people with disabilities had not received any rehabilitation services, and that there are very few trained local human resources for rehabilitation. Therefore, many CBR programmes see offering rehabilitation services as a core part of their programmes. For example, in Thailand most people with disabilities start their involvement with CBR by participation in rehabilitation and other health and medical activities. In some countries, such as China, governments have actively supported the development of rehabilitation centres and assistive technology, and recognise the need for referral mechanisms and specialists as an integral part of CBR.

Another role of the rehabilitation resource centre is to promote and facilitate inclusion in and access to existing services such as health, livelihoods, education, and social services. In each district, CBR resource centres lead a platform of service providers. Some programmes have a leading committee at local government level with participants from different government departments. These resource units have become effective coordinating agencies. In Uganda, a CBR programme is ‘spearheading a platform of service providers in the districts’.

CBR now becomes the coordinating structure between DPOs, families of people with disabilities, governments, and civil society. This community-based approach can ensure that development efforts reach the poor and marginalized, and especially people with disabilities. A presenter from Cameroon explained that ‘We want to encourage others to think about how CBR connects to broader community and development initiatives to spark connections’.
9.1.8. Financial Sustainability - government funding for CBR programs

Several presentations illustrated the importance of governments starting to take ownership of CBR and allocating a budget for it. Funding for CBR in some countries was obtained under the primary health care budget. In China, designated jobs were created in the community with the support of government subsidies and some activity budgets.

In other countries, CBR is increasingly managed with local government resources where the CBR budget is part of the local development plan with corresponding budget support. Other programmes, for example in Nepal, start with NGO support and promote cost-sharing with the community. Municipalities gradually assume the costs of implementing the project and incorporate CBR in the municipal plan. A presentation from Ecuador recommended that, once a government takes over the running of CBR, it is important to have civil society oversight to accompany the whole process of implementation of CBR with government funding.

Australian research found that many CBR programmes are still donor funded, and based on annual or bi-annual funding applications, without certainty of continuity. Some programmes stress the need for improving the financial base of the CBR programme through fundraising, while some have fundraising activities in which they meet with corporate institutions and donor agencies.

2 CBR Stakeholders

Chairs: Peter Ngomwa, Carolyn Maholo, Setareki Seru Macanawai, Mary Wickenden & Adrian Brahma.

Rapporteurs: Sophia Mohammed Sayed, Matthew Hanning, Trii Silvanto & Maryanne Mannok.

9.2.1 Participation of People with Disabilities

A presentation from Pakistan stressed that ‘the concerns and experiences of people with disability should be an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that disabled people benefit equally, and inequality is not perpetuated’.

More and more programmes have begun to apply the rights-based approach to issues of people with disabilities. A presentation from Egypt highlighted that this opens doors for the process of empowerment for people with disabilities, and enhances their participation in their own developmental process.

A presenter from Indonesia stated that it was important to ‘strengthen the full and effective participation of people with disabilities in the system and structure of local government through establishment of self-help groups of people with disabilities’.

Presentations stressed the vital role of people with disabilities and their families in inclusive community development.
9.2.2 Disabled People Organisations

While in many countries, DPOs – the united voice of people with disabilities - exist at the national level and in larger towns, they are less present in local communities and villages. Presenters from various countries e.g. Egypt and Cameroon, suggested that to ensure the full participation of people with disabilities in development, it is important for CBR programmes to establish links with local DPOs to support the national disability movement and to develop joint campaigns.

In Indonesia, for example, the leaders of DPOs participate in and influence the system and structure of local government to facilitate community-based inclusive development.

The capacity of DPOs varies. In many countries, the organisational and technical capacities of DPOs are weak and need support. CBR programmes offer support in organisational development to overcome various challenges, such as difficulties in maintaining group members, lack of resources, and holding meetings due to cost of transport. CBR facilitates the strengthening of local DPOs, and collaborates with them to carry out advocacy at the local and national levels.

9.2.3. Self-help groups

The formation of self-help groups (SHGs), informal groups of people with disabilities, is actively encouraged by CBR programmes. In Rwanda, CBR was started by initiating informal SHGs and strengthening existing formal groups. In various countries e.g. India and Uganda, CBR programmes support the formation, strengthening and streamlining of the functioning of SHGs of people with disabilities. In Uganda, they mobilized parents to form parents’ support groups (PSGs), and children with disabilities to form child rights clubs. CBR programmes are supporting people with disabilities to build their capacity to take up leadership positions by focusing specifically on what they require to enable their transition to inclusion. Group members meet to collaborate and share experiences, and these groups can be supported to form a DPO and link to national structures.

CBR programmes would benefit from joining hands with people with disabilities, and their organized groups and organizations to raise the voice for disability rights. Self-help groups and peer support facilitated relationships with others with similar experiences and increased knowledge about rights and advocacy. A presentation from Bangladesh stated that outcomes of peer support were about personal growth and development as well as community engagement and advocacy.

9.2.4. People with leprosy and Disabled People’s Organisations

Many people with leprosy are still living in former leprosaria. Self-stigmatisation of people with leprosy and a welfare mind-set have meant that people with leprosy have not joined the disability movement. Presenters stressed that it is important to focus on empowering communities affected by leprosy to assert their right to equality, and fight against discrimination. For example, programmes in India and Uganda have supported people with leprosy to start self-help groups or community-based organisations. This has enabled the organizations to advocate for their rights and freedoms, and start to interact with the wider disability movement.

9.3. CBR Workforce and capacity development

Chairs: Adrian Brahma & Ghulam Nabi Nizamani
Rapporteurs: Ting Yuen Wo & Monika Brenes.
CBR workers still lack recognition as a professional group and lack training, certification, and accountability. This is partially related to the wide range of skills and positions (from volunteers to practitioners) that make up a CBR programme. CBR programmes need a workforce with clear roles and the capacity to deliver quality services which does not currently exist. To complicate matters further, CBR has been evolving with staff taking on new roles for which they are not always equipped. This leaves programmes and training institutions in uncharted territory.

9.3.1. Types of CBR workforces

Presentations highlighted that CBR programmes have a varied workforce spanning professional staff to volunteers, depending on the focus of the programme. A common structure for most CBR programmes is the requirement for a CBR coordinator or manager to guide the programme, and to supervise the mid-level staff and community workers.

Mid-level staff will have particular skills depending on the focus of the programme. A programme that offers rehabilitation must have access to a rehabilitation professional such as occupational therapists or physiotherapists. Another programme may need someone with expertise in advocacy and working with governments.

Ideally there is one community disability worker in every village. Some programmes use the term ‘community rehabilitation worker’. For example, in Nepal this worker is contracted by the local Village Development Committee. The use of community disability workers is an advantage because they understand the culture and weaknesses of their communities. It was suggested by a presenter from India that it should be mandatory for DPOs and CBR workers to learn basic counselling skills, to listen, empathize, help articulate, build confidence, and support people with disability and their care-givers.

A community disability or rehabilitation worker performs many roles that are usually provided by various professionals. A South African presentation stated that disability-inclusive development requires a workforce equipped with skills to work across sectors and across disciplines to facilitate the delivery of services in communities. The experiences of a Malawian community rehabilitation worker revealed that they not only work with people with disabilities and their families, but also lobby and facilitate social inclusion and awareness raising. ‘I need to mainstream disability issues into …development activities… in the District Education Management, District Agricultural Development Office, the District Health Director,’ (Malawi CBR worker).

Many programmes make use of CBR volunteers and try to have them work in each community. A Columbian presentation highlighted the challenge of keeping volunteers, and recommended that volunteers need to be supported. Strategies have to be developed to avoid high turnover of volunteers.

9.3.2. Accreditation of CBR workers

Community rehabilitation workers are specialised practitioners who deserve professional recognition, and it was stressed that it was important that the position should have a job description. In China, training requirements and salaries for community workers are mandated and funded by government.

There is an overall requirement to develop proper structures for a CBR workforce, including education, accreditation, and regulation. Tajikistan recommended that CBR workers should be
recognised and national training schemes should be developed and professionalised with an approved curriculum. Also required are management and supervision systems for staff with effective links to professional cadres, motivation, and remuneration.

There is a requirement for different models of training and apprenticeship in CBR. Certification and examination processes should enable young people to choose CBR as a profession as well as empower parents of children with disabilities or people with disabilities themselves to get involved as CBR workers. CBR workers must be able to gain promotion and to develop a career path.

9.3.3. Curriculum development

A Ugandan presentation stated that CBR programmes require trained personnel with competence in appropriate interventions. A South African presenter suggested that formal training must be developed by recognised training institutions to train community disability workers, with a curriculum and learning outcomes.

9.3.4. Establishment of national CBR networks

To support the further development of CBR within countries and to exchange information and knowledge, people have been developing CBR country networks e.g. in Uganda. Networks have been developed across Africa, and the CBR African Network (CAN) includes promotion and the development of communities of practice. A presenter from Cameroon described a community of practice as a group of people who share common goals and who are interested in (and sometimes passionate about) developing and spreading new knowledge to improve understanding and action around an issue\(^1\). They recognized that face to face meetings are becoming less frequent as people have greater access to social media and internet communications. In Ecuador, a CBR network was established by civil society and government.

In many places, there are very few or no professional development opportunities for CBR and rehabilitation providers who are committed to inclusive development. The network offers people an opportunity to talk and share experiences and learn from each other.

9.4. Monitoring, evaluation, and research

Chairs: Svein Brodtkorb, Goli Hashem, Kate Sherry, Andrea Vogt & Musonda Siame.

Rapporteurs: Frank Velthuizen, Catherine Sykes, Graziella Lippolis, Albert Chaki & Moses Kiwanuka.

CBR programmes should have a clear management structure to function effectively. A good management system will ensure quality of service, effectiveness, and efficiency. It was stated that CBR is complex and requires clear plans and targets, a competent workforce, staff support and training, as well as the creation of a database to monitor change.

9.4.1. Planning, Monitoring and Evaluation

Various presentations touched on the requirement to develop more robust planning and monitoring systems for CBR programmes, and to require plans to articulate the change to which the programme wants to contribute. Participatory planning was stressed in many presentations, especially the active

\(^1\) Adapted from Wenger-Trayner

http://wenger-trayner.com/introduction-to-communities-of-practice
involvement of people with disabilities. To be able to monitor change it is necessary to have baseline information and specific targets about what changes a programme wants to achieve.

Various methods have been used by CBR programmes to collect data.

In Malawi, a questionnaire has been developed to collect information about individual people with disabilities and their functioning, which they can feed into a central computer programme. Thailand does the same and uses an assessment form based on the International Classification of Functioning. With this, information change is monitored over time.

In order to evaluate CBR programmes, CBM has developed a questionnaire that asks people with disabilities to reflect on changes in their lives and those of their families, on changes in their local communities, and changes at national level. It asks: if anything has changed, what can be learnt from the changes and how can the CBR programme further improve by doing things differently?

Another example is Light for the World’s tool that measures the levels of disability inclusion in programmes. The tool allows self-assessment and supports programme planning.

Lessons learned were that monitoring tools must be simple and easy to use, use a language that people connect with, and assist projects to determine how far their work contributes towards a more inclusive society.

9.4.2. Disability data collection

The collection of disability data in a particular district is a contested issue due to the various definitions of disability used. One tool presented was the Rapid Assessment of Disability (RAD) survey tool. It estimates the number of people with disabilities in a community using ‘functioning’ as a measure, identifying individual perception of well-being, participation and inclusion in the community, barriers restricting participation, and comparing the data to those without disabilities (case control). Limitations are that the tool is not rapid, is paper-based and provides only a snapshot. As it is a self-reported assessment, it provides no details on diagnosis of conditions, nor cause of disability, nor factors leading to barriers to participation.

9.4.3. Research

Research was seen as valuable and essential for the further development of CBR programmes, as well as for the promotion of evidence-based practice. A presenter from Pakistan stated: ‘Evidence-based action research should be promoted in CBR programmes for effective planning, resulting in sustainable community-based inclusive development’.

One way to do this research is to link universities with CBR programmes. A CBR programme in Ghana recommends that this must be planned carefully so the research adds value, and builds on programme practice rather than it being seen as something done for someone that takes extra time and money. CBR often deals with complex issues, and universities can support the process of capturing the complexity of issues by combining research methods and ensuring the use of the right tools, correctly translated and followed-up.
9.4.3.1. Participatory research

Inclusive research with people with disabilities is a growing trend internationally (O’Brien, McConkey & García-Iriart, 2013). However little work has been done in this area, specifically with people with intellectual disabilities in Africa. A South African pilot study was presented, whereby people with intellectual disabilities were included as co-researchers. The researcher found it a new and rewarding experience, as co-researchers were committed to the process. One co-researcher explained: ‘I learned a lot being the interviewer, how to approach the person and how to talk to the person, and also to listen to the person, what he’s saying. You mustn’t interrupt until the person has finished what they’re saying’.

9.5. CBR in practice

Chairs:

Rapporteurs:

CBR programmes lobby for programmes, goods and services that are available, accessible, acceptable and of good quality, and give support to people with disabilities. CBR programmes support rehabilitation and inclusion in health, education, livelihoods, and empowerment for people with disabilities and their families.

9.5.1 Rehabilitation in CBR

The process and role of rehabilitation in CBR programmes was described in numerous presentations (e.g. from Uganda, China, South Africa, Malawi, and Pakistan). The following is a list interventions and services needed:

- Mobilize communities and identify people with disabilities who require and have a right to services.
- Assess people with disabilities and their environmental situation.
- Make referrals, e.g. to physical or mental health services, understanding that referral mechanisms are an integral part of CBR. This may include surgery.
- Provide therapy / rehabilitation: apply essential methods, procedures and techniques to address impairments and functional limitations, provide basic interventions to improve participation in life, and to supply or refer for assistive appliances.
- Train individuals and families to continue with the therapy programme to take charge of it.
- Facilitate access to assistive devices and appliances in education: enrolment of children with disabilities into education, with early intervention to prepare them for school, and teacher training to ensure inclusive education.
- Support inclusion in education.
- Raise awareness of, and lobby for, the removal of social and environmental barriers.
- Provide rehabilitation to enable participation in livelihood activities, skills development, employment opportunities, and inclusion in loan and savings schemes.
- Support the development of self-help groups and parents' groups.

Presentations showed how people with disabilities need to take a central role in rehabilitation and to participate in the development of individual plans and goal-setting for rehabilitation. In addition, they require support to form self-help groups. In many countries mothers are the main care-givers, but in Colombia it was noted that fathers and brothers have become more actively involved in the rehabilitation children with disabilities.

Some programmes offer comprehensive rehabilitation services to people with any type of disability or, in some cases, to targeted groups e.g. people with leprosy or people with mental health issues. Some programmes provide certain aspects of rehabilitation, such as services for improved mobility.

Many presentations called for the further development of a workforce for rehabilitation. The presentation from Afghanistan recommended that more efforts could be made to train professionals like speech therapists and audiologists, occupational therapists, clinical psychologists and mobility trainers.

9.5.1.1 Assistive devices – wheelchairs

A number of papers discussed the need for assistive devices in general. They spoke in greater detail about how to develop wheelchair services in different countries. Wheelchair services are not well developed in most low and middle-income countries. There is a lack of skills and a lack of affordable and practical wheelchairs. CBR workers have an important role to play in wheelchair provision and to ensure that the eight service steps as recommended by the WHO (WHO 2012)2 are implemented.

9.5.2 Hygiene and sanitation – disability inclusive WASH

Some CBR programmes have become more active in general public health issues and link up with other initiatives, such as WASH (Water, Sanitation and Health). An initiative in India created conditions for attitudinal change in families and communities, and among school and government officials to recognize the sanitation rights of people with disabilities.

9.5.3 Health - including mental health

People with disabilities have the same rights to health services as any other person, and they may also require specific health care and rehabilitation services for their impairments.

The health situation in many low and middle-income countries suffers from a lack of resources and facilities. It was noted that people with disabilities experience various barriers to health care services such as physical inaccessibility, costs of transportation, treatment cost and limited availability of services. Health staff have limited capacity and lack knowledge about disability, resulting in inadequate care, bad treatment or people even being denied care as described by a presentation from Afghanistan. In a South African study, it was found that in some countries the cost of health care for people with disabilities is routinely higher than for people without disabilities. In addition, people with disabilities face a number of non-monetary costs such as the need for an assistant, extra time, energy and people to make many wasted visits to clinics. A presenter from Bangladesh stated that there is a lack of proper information and referral systems, policies are not implemented, and there are inadequate specialized rehabilitation facilities. Many people with psycho-social disabilities

in low and middle-income countries are unable to access appropriate services, and have never seen a doctor for their mental illness.

A South African presentation stressed the need to build more relational and empowering health systems with primary healthcare as the key place where personal relationships can be built. It was also suggested that psychiatric services must be developed as part of the primary health care system.

CBR programmes in collaboration with DPOs have started to lobby ministries of health for a more inclusive health care system, as well as for the development of good-quality rehabilitation facilities at sub-district level hospitals. A CBR programme in Bangladesh has successfully supported health services to become more accessible and inclusive through training and technical support to the health facilities.

An important component is the development of positive attitudes among health staff towards people with disabilities and acceptance of rehabilitation under the ministry of health. It was stressed that information about disability, health and rehabilitation should be included in the training for doctors, community health workers, midwives and nurses.

A recommendation was made to create a model health infrastructure which is accessible to all in each country. In order to overcome some of the barriers to accessing health care, it was proposed to have a one-stop service from holistic assessment to accessible good-quality treatment.

9.5.3.1 Psycho-social rehabilitation

CBR programmes are in a key position to support people with psycho-social disabilities. Three examples were discussed: (i) In Cameroon, CBR supports the development of livelihood activities to enable people with mental health disabilities to contribute to their families and communities; (ii) in the Philippines, a monthly mental health clinic was organized along with a support group for people with psycho-social disabilities and their families; (iii) in China, community mental health centres were developed to assist people with personalized treatment and rehabilitation in order to promote their social inclusion. The units are organised inside the existing primary health care system or in autonomous structures closest to the place of residence of the people with mental health issues.

9.5.4 Disaster Risk Reduction

A presentation from South Sudan discussed how they developed a CBR programme in an internally displaced people’s (IDP) camp. The programme promotes the mainstreaming of disability into the identification and registration process, as well as into protection services, food security, water and sanitation, health, education and social services. A positive example was ‘sports for peace’: the team became not only a good advocate for disability inclusion but it also promoted peace in Juba. Because of this initiative, fighting between youths from different tribes in the camp was reduced.
9.6 Education & Livelihoods

9.6.1 Promotion of early childhood development

To ensure children with disabilities and other marginalized children receive the services essential to access good quality education, it is important to identify the children early and ensure that they are linked to available services. The problem faced by many CBR programmes is that there is a general lack of pre-school provision and early childhood development centres. Some CBR programmes have become involved in initiatives to develop pre-school programmes. For example, in India it was possible to ensure that training kits and resources became inclusive of the needs of children with disabilities.

9.6.2 Access to primary education

If the right to education for all is to be realised, it is necessary that all learners - including learners with disabilities - can enjoy good-quality education that provides a basic curriculum and enriches lives. However, many children are excluded from education as services in low and middle-income countries continue to face many difficulties, such as large classes, few and poorly trained teachers, and a lack of teaching and learning materials. In Tanzania, rigid teaching methodologies and the focus on examinations hinder children with disabilities from proceeding to higher levels of education. Seeing these enormous challenges, teachers and parents wonder how the inclusion of children with disabilities in this system is possible.

CBR programmes support governments in their efforts to strengthen the capacity of schools to reach out to all learners. They provide guidance about the modification of buildings to increase the physical accessibility, such as the construction of ramps. They try to support a change in the school ethos so that it includes and accommodates learners with diverse backgrounds including those with disabilities. CBR also suggests modifications to teaching content as well as to teaching approaches used in class. They lobby ministries of education to take responsibility for the provision of specialised teaching resources for learners with disabilities in schools. Some CBR programmes assist ministries with the capacity development of mainstream teachers, to ensure that teachers have the basic skills to assist all learners in regular schools. In countries where they have itinerant teachers, they are too few and do not cover the whole country. The monitoring of children with disabilities on how they are coping in class and whether support is adequate, is also an important aspect that some CBR programmes are involved in.

The CBR programme from Malawi suggested that a link between schools and the community should be established to make sure that learning is supported by parents through disability committees, parent support groups and parent-teacher associations. They facilitate the representation of parents of children with disabilities on school committees. Some programmes promote the child-to-child methodology and have started child rights clubs. This involvement of children has increased the number of children with disabilities enrolled in schools, and resulted in more children realising their rights and fighting for them.

9.6.3 Livelihoods

A study from Canada showed the importance of being involved in livelihood activities. ‘I’d like to get a job, a small job, even part time. I can be useful. I’ve been useful to lots of people and I can still be useful in many things. The financial aspect would help … so yeah, a bit more money and a few more interesting things to do’.
The pressing, often overlooked, demand of people with disability is to develop livelihoods and improve their economic situation. A presentation from Bangladesh stated that the dual goals of empowering individuals and reducing poverty at the household level can be achieved through closely linking rehabilitation and livelihood support. To be able to give advice, CBR programmes have to familiarise themselves and carry out a local market study to determine what the most profitable trades are in that community and to identify potential employers.

9.6.4 Vocational training

CBR programmes are supporting youths with disabilities to take up apprenticeships and on-the-job training in their local communities, and to take an active part in brokering these relationships. In Bangladesh, CBR facilitates the cooperation and coordination of the multi-stakeholder approach to create more skills training and employment of people with disability. For example, they link with mainstream vocational programmes and encourage them to include trainees with disabilities. Similarly, in Afghanistan guidelines have been developed for integrating people with disabilities into mainstream vocational training.

Some CBR programmes also offer training locally, often in collaboration with local trainers such as literacy and business management training at the community level. In Afghanistan, women with disabilities have greater access to self-employment with the support of business development officers and family members. The training is offered in their local communities. In India, a programme found that trades in community-based training are more flexible and can be tailored to community demand, whereas institution-based centres are more rigidly structured.

9.6.5 Employment

In Bangladesh, CBR encouraged potential employers to create employment opportunities in factories for people with disabilities. The recruitment of people with disabilities was ensured in more than 100 factories in Bangladesh. Guidelines about inclusion were given and used by more than 72 factories (related to accessibility, reasonable accommodations, recruitment, and consideration of people with disabilities in the company guidelines). Other CBR programmes advocate an employment quota system for people with disabilities. In Bangladesh, they are lobbying for tax exemptions for recruiting people with disabilities.

Linking people with disabilities with employment opportunities demands new ways of engaging with employers. An innovative solution was developed in Hong Kong where a recruitment database for people with disability looking for employment was set up jointly by government, NGO, and private sectors.

9.6.6 Microfinance

Access to finance by people with disabilities and vulnerable groups is a prerequisite for poverty reduction, community cohesion and social inclusion. Some CBR programmes actively work with local savings and loans schemes, and have achieved access to loans for many people with disabilities. In India, 3,893 people with a disability are enrolled in mainstream financial processes (bank accounts, insurance and direct transfer of benefits). In Pakistan, people with disabilities have been able to benefit from the Pakistan Poverty Alleviation Fund, which financed cumulatively over 6.9 million micro-credit loans.
10. Interactive sessions summary

The three plenary Interactive sessions were facilitated by Derek Hooper.

Group facilitators:
Darryl Barret, Joerg Weber, Theresa Lorenzo, Judith van der Veen, Paul Edward Muego, Alice Ngangwa and Olmedo Zambrano.

The purpose of the Interactive sessions was to give Congress participants the opportunity to engage in a dialogue about the current status of CBR and the way forward. The outcomes of the Pulse survey and focus group discussions about CBR which had taken place prior to the Congress formed the basis of the sessions.

The process used consensus to describe a way forward for CBR. Each day had a theme linked to the morning’s abstracts:

Day one: Stakeholders and sustainability
Day two: CBR in practice
Day three: The way forward

Each of the three sessions started with a short video which showed the outcomes of the PULSE survey and focus group discussions as they related to the Congress theme of the day. The participants were then invited to discuss two questions related to that theme.

Note - the discussions in the interactive sessions were lively and wide-ranging; the discussion points that emerged from the sessions were the product of ‘brainstorming’ and so, where action was identified as being necessary, it was not always the case that the agent responsible for carrying out that action was identified. In practice, the agent will always be one or more of:

- The family
- Civil society
- CBR programmes
- Governments
Day 1: Stakeholders and sustainability

Question 1: What factors will make CBR more sustainable and secure by 2021?

Key discussion points from the groups:

Develop a shared understanding of CBR because currently there is a lack of clarity among CBR practitioners and other stakeholders. This means practitioners need to:

- Clarify what CBR is and develop a shared understanding.
- Address questions of CBR development, its sustainability, its training and support prerequisites.
- Ensure everyone understands CBR is a disability-inclusive development strategy.

Create awareness about CBR as a bottom-up approach to disability inclusion and implement the SDGs and UNCRPD through a community-based strategy. This means we need to:

- Move disability and inclusion into the mainstream development agenda.
- Address the lack of recognition of CBR’s potential among stakeholders.
- Create awareness among governments, UN and development agencies.

Governments take up their role as duty-bearers. This means governments:

- Identify themselves as the main planner, funder and implementer of policies and services.
- Give leadership to CBR to ensure its development and sustainability.
- Take responsibility to collaborate with DPOs.

Promote leadership and participation of people with disabilities and their families. This means we need to:

- Ensure CBR programmes work closely with people with disabilities and DPOs, and vice versa.
- Use programmes to support capacity-building of people with disabilities to enable them to take up leadership positions.
- Have governments and people with disabilities collaborate (and with other stakeholders where necessary) on promoting disability mainstreaming and inclusion.
- Facilitate collaboration among stakeholders (including DPOs, ministries, and civil society stakeholders), and facilitating joint planning meetings for development.
- Support families to enable the development of their family members with disabilities.

We need more evidence about effective practice. This means we need to:

- Collect and use evidence to show the effectiveness of CBR.
Question 2:

Looking forward to 2021, where should government responsibility for CBR funding and delivery be placed?

Key discussion points from the groups:

Governments work through CBR to facilitate disability inclusion and mainstreaming.

This means governments:

- Take responsibility as duty-bearers to set up disability coordination units that take up an overall coordination and monitoring role (e.g. a unit in the President’s office or the disability ministry, or a special section in a ministry, or a free-standing disability monitoring unit).
- Define the purpose of the CBR unit at national and local levels, to facilitate and promote inclusion and mainstreaming throughout all the different ministries (social affairs, health, education, labour, transport, etc.) and departments.
- Give authority to the CBR unit to work across sectors (ministries) and collaborate with other stakeholders.
- Provide funding for CBR coordination by a particular ministry or department.
- Create a defined structure and employ qualified staff for CBR coordinating.
- Make community-based CBR workers the co-ordinators of disability-inclusive development programmes in government and NGO sectors.

Governments draft strategies and plans

This means governments:

- Develop a disability-inclusive development strategy and implementation plan.
- Ensure people with disabilities benefit from different policies and services.
- Take overall responsibility for implementing and monitoring the strategy – which everyone (communities, DPOs, other sectors and stakeholders) contributes to and benefits from it.
- Set targets and indicators, so it is easier to allocate budgets and track expenditure.
- Use monitoring systems to generate more data to support future planning.
- Use disability data from government, NGOs and DPOs to analysed and inform budget allocation.
- Cease allocation of disability budgets to a particular agency or ministry and instead require each ministry or organisation to mainstream disability and allocate its own budgets.
- Share responsibility for disability inclusion and service delivery between government departments, NGOs, and DPOs.

Coordination units need to:

- Ensure disability inclusion and mainstreaming across sectors and ministries at all levels.
- Support ministries, departments and stakeholders to plan for inclusion and to monitor implementation.
- Promote and facilitate the development of disability implementation plans and disability-inclusive sector plans by all ministries or local government departments.
• Establish criteria and powers to ensure the adequate performance of its duties, e.g. to have the power to monitor the plans of other ministries.

Disability inter-agency committees / councils need to:

• Acknowledge CBR as a multi-stakeholder strategy for inclusive development and promote shared responsibility.
• Consider disability mainstreaming in the policies, plans and programmes of all government sectors, ministries and departments at all levels (from local to national).
• Recognize that CBR requires the establishment of an inter-ministerial or inter-agency committee (e.g. national disability council/committee).
• Establish a strategic body (inter-agency) at the highest level of government that has the authority to ensure the inclusion of disability in all sectors. The inter-agency unit or council would exist at local government level.

Capacity development

Governments need to:

• Increase their understanding and capacity around disability and inclusive development.
• Make the inclusion of disability a part of the planning process and not an afterthought.
• Educate and train government officials on disability rights, and include disability in plans which have targets and monitoring systems to make disability visible.
• Invite DPOs to play a role in building the capacity of government departments.
• Bring together people with disabilities, DPOs and CBR programmes to build capacity for inclusion.

Fig 1: Disability Coordination Unit in National Government Structure

Fig. 2: Disability Coordination Unit in Local Government Structure
Day 2  CBR in practice

Question 3:
Looking forward to 2021, how important are these issues for CBR practitioners and why?

Key discussion points from the group:
- Accreditation for practitioners’ skills and knowledge.
- Core curriculum for CBR training and development.
- Training and support on advocacy and lobbying.

CBR key principle relevant to accreditation, curriculum and training:
Families and communities are at the core of CBR.

CBR workforce
A curriculum of knowledge, skills and attitudes for CBR practitioners is required, informed by practitioners at the community level. Essential coverage would include:
- To clarify and map out what workforce is needed for CBR.
- To define the capacities of CBR practitioners on a broad range of issues.
- To clarify what type of practitioners are needed.
- To identify who could accredit training courses.

Status of CBR workforce accreditation
The status of CBR workers is often not recognised. Prerequisites for accreditation are:
- To recognise CBR as a ‘profession’ with different cadres.
- To ensure accreditation for all CBR workers at different levels (managers, supervisors, community disability workers, volunteers, technicians etc.).
- Through accreditation, to draw people into the profession and contribute to better retention and career development.
- To recognize the contribution of volunteers to add to the quality of work.
- To incorporate CBR staff in national structures and payment scales.
- To establish associations of CBR workers and professionals which would be able to support the development of career pathways set minimum standards, and clarify roles and types of services.
- To ensure CBR training is accessible and cost is not a barrier.

There were some fears that accreditation might stifle innovative practices, and that accreditation might exclude some workers who do not have a high educational level and are very good at their work. To avoid this, it was recommended that courses and training institutions recognise prior learning, and use ways of obtaining accreditation through practical training such as apprenticeships.

CBR workforce training
It requires a global approach with regional/local adaptations. Stakeholders would work together:
- To develop a global CBR core curriculum to help improve recognition of CBR.
• To develop a curriculum to equip practitioners with skills and knowledge for standardised service delivery.
• To ensure the curriculum is flexible enough to be easily adaptable to local contexts.
• To develop certified training courses for different cadres.
• To provide training in recognized institutions (colleges, universities).
• To encourage institutions to set up relevant CBR training courses.
• To establish a global core curriculum with minimum standards and perspectives.
• To ensure that the training meets the range and variety of situations known to exist.
• To ensure that training is related to the local environment.
• To blend knowledge and theory with practice.
• To amend training courses periodically to stay in touch with changing global and local contexts.
• To promote continued professional development to ensure quality.

Training on disability rights and inclusion in general courses to increase awareness of disability:

• To change attitudes and increase awareness, including modules on disability and CBR in existing schools and professional curricula (teachers, transport, finance officers, roads).
• To develop modules on disability and inclusion that can be used and adapted across all professions. [include training on rights, equality, policy – with strong family and community focus.]

**Question 4:**
**Looking forward to 2021, what training and support will benefit CBR practitioners and why?**

**Key discussion points from the group:**
Major themes to be part of CBR training:

**Disability – rights and equity - would include:**

Training on understanding the international and local policy and development frameworks.

• Disability, disability inclusion and the centrality of people with disabilities and the family in CBR.
• Rights, equity, policies, UNCRPD/SDGs principles, using a rights-based approach.
• Concepts of development, community development, and inclusion.
• Local, national, international policy and governance structures.
• Diversity issues such as race, gender and other issues such as child safeguarding.

**CBR concept would include:**

Training on the clarification of the concept of CBR and the removal misconceptions.

• Core concepts of CBR.
• Disability mainstreaming and inclusion into local and national Government plans and services (government planning, budgeting and monitoring systems).
• Multi-sectoral approach.
• Universal design and accessibility.
• Unique role of CBR as a coordinating mechanism.

Support to people with disabilities and their families would include:

• Basic knowledge and competencies in:
  - Health conditions and impairments including mental health.
  - Basic rehabilitation skills: technical skills to work with individual children and adults with disabilities and their families, to address functional limitations and participation restrictions, and to offer psycho-social support.
  - Person-specific engagement: assessment and development of individual intervention plans, referral systems for continuing care, therapy and rehabilitation skills, and provision of assistive technology.
  - Assistive devices and adaptations for the local environment.

• Technical skills in areas such as accessibility and creating a barrier-free environment.

• ICT innovations, assistive devices.

Advocacy would include:

• Drafting a strategy and plan with stakeholders
• Advocacy messaging.
• Types of advocacy.
• Targeting advocacy to particular stakeholders.

Networking would include:

• Collaborating and networking within a broad area of stakeholders.
• Attracting more specialised staff.

CBR management would include:

• Leadership qualities: knowledge of management, human resources, resource mobilization, and fundraising.
• Management skills: project cycle management, planning, monitoring and evaluation, record keeping, data management, and research.
Day 3: The way forward

Question 5: 
Looking forward to 2021, what practices will make CBR unique and distinct from other initiatives?

Key discussion points from the group:
CBR as a unique strategy

CBR is like a hand with its fingers: the 5 components - health, education, social, livelihoods and empowerment; the palm = people with disabilities and their families; the wrist = government and NGOs all interacting towards inclusion at community, district, provincial and national level.

- CBR is a disability-inclusive community development approach. It is community-driven, adapts to the community’s needs, reaching people through participation and coordination, empowerment and sustainability. CBR is adaptable and context-specific. It is located in the community, with the community.
- CBR/CBID has a common global framework. It is a holistic approach to disability-inclusive community development. It facilitates sectoral mainstreaming, building strategic networks for sustainability and accessibility for all.
- CBR is a strategy to build capacity at grassroots level, targeting many sectors and groups (people with disabilities, their families, other vulnerable groups, the government, NGOs, and other stakeholders) all of whom contribute to disability inclusion at local, national, regional and international development. It is a model that can be used by all.
- It is bottom-up / trickle down (bottom-up is practices, trickle down is policies).
- It is an inclusive and rights-based strategy guided by the principles of the UN Convention on the Rights of Persons with Disabilities.
- In CBR, people with disabilities take the lead. The needs, demands, and aspirations of people with disabilities are at the centre. It facilitates and supports the empowerment of people with disability and their families.
- It harnesses the goodwill and commitment of people with disabilities, CBR practitioners, volunteers, and care-givers within the community.
Question 6:

What should the CBR Global Network be doing to move CBR forward to 2021?

**Key discussion points from the group:**

(i) Internal - strengthen the Global Network

Overall
- To clarify the purpose of the network.
- To take on a leadership role (WHO to be more in the background)
- To support the grassroots – to connect the local with the global more dynamically – ensuring local voices are heard, putting in place a community of practice.

Governance
- To strengthen its capacity at all levels as a resource.
- To improve the efficiency of the operational structure (personnel, administration, pool of experts).
- To develop a CBR Strategy and Action Plan.
- To mobilize resources to implement activities and facilitate more frequent meetings (e.g. thematic meetings, round table meetings).
- To develop minimum standards for CBR.
- To build internal organisational capacity.
- To introduce and use monitoring systems.

Support the regional and national networks
- To build the capacity of and strengthen regional networks.
- To organize and support the local and national networks through training.
- To promote the replication of best practice.

(ii) External – strengthen the Global Network

Training and capacity development
- To support countries to develop a common understanding about CBR.
- To lead the development of core modules on CBR with guidelines for local adaptation and quality control, including a combination of face-to-face and online modules.
- To support the strengthening of national networks.

Knowledge management and sharing
- To support the exchange of knowledge, information and resources.
- To develop and maintain an up-to-date website.
- To document and disseminate good practice e.g. evidence-based practices, minimum standards.
- To create an open resource on evidence and research, and a knowledge-sharing platform.
Coordinate & raise awareness about CBR in partnership with regional and national networks

- To develop communications materials, and plan and implement joint campaigns (with regional networks).
- To facilitate the development of a common CBR understanding and develop materials to share information about this
- To develop a unified terminology.
- To develop and disseminate an operational and management framework for CBR.
- To create awareness of the CBR indicators manual and promote its use by members to strengthen the monitoring and evaluation of programmes.

Networking/ advocacy

- To collaborate and network strategically to promote the rights of people with disabilities.
- To engage with high-level stakeholders (governments, mainstream organisations) for CBR policy development and attitude change.
- To influence and lobby governments and donor agencies to support CBR, especially for funding and budget allocation.
- To develop joint advocacy with DPOs and NGOs to enforce UNCRPD implementation at the country level and in the development of national plans.
- To lobby UN organizations to accept CBR as a global strategy for inclusive development.
- Carry out joint advocacy with UN agencies to influence policy and promote CBR.
11 Closing ceremony

During the closing ceremony, the draft Congress declaration was presented and adopted (circulated in the CGN newsletter and see section 12).

The CGN president, Balakrishna Venkatesh, thanked the Malaysian government and the local organising committee for their excellent organisation of the Congress. He announced that the next CBR World Congress would be held in 2020. Possible host countries are Uganda, Zimbabwe, and Chile.

Dr Cieza Alarcos Cieza from WHO, in her closing observations, declared that WHO will launch a call for action to promote rehabilitation as part of universal health coverage. This includes rehabilitation in the community. She announced that the INCLUDE eLearning platform was now available at http://include.edc.org/ or via the WHO website, and launched an online training program on the CBR Guidelines (http://www.who.int/disabilities/include/en/)

Closing speech

Her Excellency, Datuk Hajah Azizah Datuk Seri Panglima Haji Mohd Dun, Deputy Minister of Women, Family and Community Development closed the Congress with the following remarks:

‘Congratulations to the team who made this event a reality. The Congress has definitely provided knowledge, enhancing platforms and networking for all participants. It has emphasized how to implement the Community-based Rehabilitation (CBR) concept as a strategy in community development involving persons with disabilities. I would like to take this opportunity to thank all speakers for their valuable insights, ideas, experiences and inspirations. This Congress demonstrates that much progress has been achieved across the world to improve the lives of persons with disabilities through CBR. Disabled people’s organisations, many of whom are represented here, are working with their governments to drive change for all citizens. We have a long way to go and we need to continue to work and act together to drive this change for a more inclusive region. Before I conclude, I am very glad that an arrangement has been made for the delegates to visit eleven CBR centres in Malaysia.
On the other hand, I would like to extend my deepest appreciation and heartfelt thanks to the joint organisers namely CBR Network Malaysia and the Malaysian Council for Rehabilitation as well the Ministries, for pulling in all resources to make this Congress a great success and I’m very glad to be a part of this significant and meaningful Congress.

Lastly, a huge thank you to all the participants who have attended this Congress, I hope the Congress has been a rewarding experience for you. I now have the pleasure in closing the 2nd CBR World Congress in Kuala Lumpur.’

The International Organising Committee and the National Organising Committee of the 2nd World CBR Congress
In summation of the proceedings and deliberations of the Congress, the following declaration was agreed by participants:

The 2nd CBR World Congress, proudly hosted by the Malaysian Government, CBR Global Network (CGN), CBR Network Malaysia (CNM), Malaysian Council of Rehabilitation (MCR) and the World Health Organization (WHO) has brought together practitioners, people with disabilities, development agencies, governments, and academics from across the globe.

This 2nd CBR World Congress joins the celebration of 10 years of the Convention on the Rights of Persons with Disabilities and welcomes the Sustainable Development Goals, which recognize equity as central to development.

Presentations and discussion in plenary, and parallel and interactive sessions, point to a vibrant CBR world that is engaging (to varying degrees) with a disability-inclusive development agenda. There is a growing recognition of the potential of CBR as a key bottom-up strategy to support countries to achieve their development goals by building an inclusive world.

In order to create, nurture and develop an inclusive society, there is an obligation to mainstream disability issues across sectors, ministries and departments. Segregated and unequal systems for people with disabilities are detrimental to society and come at a high cost for people and development.

We, the delegates of the 2nd CBR World Congress 2016 in Kuala Lumpur, Malaysia, call for:

- Governments, as the duty bearers, to take responsibility for sustaining CBR programmes, managed together with disabled people’s organisations and key community/national stakeholders.
- All development plans, from community to national levels, are inclusive. (External) CBR organizations are enablers and resources for communities and to help in enhancing the quality of health, education and livelihood systems.
- Greater engagement between disabled people’s organizations, governments, non-governmental organizations, and CBR at the local, national and international levels to achieve inclusive development, including through participatory planning.
- CBR Global Network and relevant stakeholders to develop a common, flexible CBR curricula for CBR practitioners.
- Multi-sectoral coordinated Government commitment and involvement in disability mainstreaming at local, provincial and national level to better secure CBR funding and workforce.
- To promote the empowerment of people with disabilities, their families and carers to take increased leadership in disability inclusion activities in their communities.
- The integration of disability inclusion principles into the curricula of professional and government official training.
- To decentralize service delivery mechanisms, which enable local participation and improve accessibility.
• Public and private entities to make further efforts to ensure inclusive environments, communication, information and programmes through the principles of universal design.

• Governments, UN, and development and humanitarian agencies to ensure people with disabilities are included in food security, WASH, and community resilience programs.

• WHO and governments to advance the rehabilitation agenda and for CBR programmes to advocate with governments for rehabilitation services for all who need them.

• Governments to promote WHO’s GATE initiative to ensure equitable access to assistive devices.

• Governments to ensure that children with different disabilities can exercise their right to good-quality inclusive education.

• Governments and international entities, along with CBR, to continue strengthening efforts in inclusive formal and non-formal employment for all citizens.

• CBR to reaffirm its commitment to support the inclusion and empowerment of people with psycho-social disability, leprosy, and older people experiencing disability.

• Utilizing the CBR strategy, people with disabilities should be included and have full and effective participation in the process of DRR prevention and mitigation, preparedness, emergency response, and recovery/rehabilitation.

• National and international funding agencies to invest for CBR to conduct action research, especially that which is driven by the Global South and is focused on:
  - monitoring and evaluation
  - how CBR contributes to development and human rights agendas.

• CBR practitioners and governments to engage in evidence-based practice.

Ensuring commitments to these calls for action will contribute to a future where no one is left behind.
Appendix 1

Useful Information

https://cbrglobalnetwork.wordpress.com
venktesh.bala@gmail.com  email ID of the Honorary President of the CBR Global Network.

Postal Address for the CBR Global Network:

Action on Disability and Development, India (ADD India),
4005, 19th Cross, 2nd Stage Banashankari,
Bangalore 560070
India
Mobile: ++(91) 9676286388

Appendix 2

Acknowledgment and thanks to:

Ministry of Women, Family and Community Development, Government of Malaysia for funding and co-hosting the Congress.

Ministry of Tourism, Government of Malaysia for funding the Congress.

World Health Organization (WHO) for funding and co-hosting the Congress.

CBR Network Malaysia (CNM) and Malaysian Council of Rehabilitation (MCR) for organising the Congress.

The National Organising Committee and the International Organising Committee for organising the Congress

Judith Van der Veen, World Health Organization (WHO) for writing this report.
judith@judithvdveen.com

Alison and Simon Partnership Services for rewriting and editing the Congress report.
contact@asps.services

Derek Hooper, Equality and Diversity Consultant, for designing and facilitating the interactive sessions, and reviewing the final draft of the report. derekhooper3@icloud.com

Dr. Alarcos Cieza, Coordinator of Prevention of Blindness and Deafness, Disability and Rehabilitation Unit at the World Health Organization, for reviewing the draft report. ciezaa@who.int

Karen Heinicke-Motsch, Global Adviser Community Based Inclusive Development, CBM for reviewing the draft report. Karen.Heinicke-Motsch@cbm.org

Marieke Boersma, CBR and Inclusive Development Advisor, Light for the World, for reviewing the draft report. m.boersma@light-for-the-world.org

Dr. Deborah Castle, ED.D, Senior Consultant, People Development Ltd. Canada. Associate Teaching Staff, Coady International Institute, St. Francis Xavier University Canada, for reviewing the draft report. debbiecastleafrica@gmail.com

Peter Coleridge, consultant in disability and development, for reviewing the draft report. peter.coleridge@googlemail.com
Technical committee for review of conference abstracts and programme speaker decisions:

Head of technical committee: Karen Heinicke-Motsch kheinickemotsch@cbmus.org
With support from the CGN Chair: Balakrishna Venkatesh venktesh.bala@gmail.com

Asia and Asia Pacific:
Ghulam Nabi Nizamani ghulamnabi.nizamani@gmail.com
Tulika Das das.tulika1@gmail.com
Gautam Chaudhury gautamchaudhury@hotmail.com
Norlida Binti Jaafar norridaj@gmail.com
Ranjith Kaur
Ahmad Razi
Norminsham Abdul Karim

Middle East:
Alaa Sebeh alaa1234@gmail.com
Malek Qutteina mquetteina@yahoo.com, mquetteina@gmail.com

Africa:
Pascal Ahidjo: pahidjo@yahoo.fr
Carolyne Maholo: carolmaholo@gmail.com

Latin America and the Caribbean:
Solangel: solecita_co@yahoo.com

Europe and North America:
Peter Coleridge peter.coleridge@googlemail.com
Cindy Greer Cindy.Greer@nhf.no
Mary Wickenden m.wickenden@ucl.ac.uk
Barney McGlade barney.mcglae@cbm.org
Feedback report

On the pre-Congress PULSE survey and focus group discussions

September 2016

Prepared for the 2nd CBR World Congress
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Executive Summary

This feedback report summarises results from a PULSE survey and focus group discussions with the aim of informing and stimulating discussions in interactive sessions for the 2nd CBR World Congress in September 2016. The feedback process was a collaboration between the Global CBR network, World Health Organisation (WHO) and International Disability Development Consortium (IDDC) and included input from over 200 survey respondents and focus group participants globally.

Findings from survey questions and focus groups have been categorised into three themes, in the following way:

1. Stakeholders and sustainability
   1.1 Sector responsibility
   Q7 – In the country I work CBR falls under the responsibility of...
   1.2 CBR stakeholders
   Q12 – Rank the following CBR stakeholders according to their importance
   Q13 – Is/are there any other important stakeholder(s) not mentioned above?
   1.3 Biggest challenges for sustainability
   Q17 – The biggest challenges for the sustainability of CBR are...
   1.4 Funding
   Q18 – What are the sources of financial resources for your work?

2. CBR in practice
   2.1 CBR training
   Q10 – What I know about CBR I know from... (select all that apply)
   2.2 Biggest barriers to CBR implementation
   Q11 – What is the biggest barrier to the implementation of CBR?
   2.3 Career development
   Q14 – Is there an opportunity for people to make a career for themselves in CBR?
   2.4 Curriculum development
   Q15 – There is a need to develop a global curriculum for CBR
   Q16 – There should be a professional association that represents people working in CBR
   2.5 Research in Practice
   Q19 – Do you make use of research results in your day-to-day work?

3. The way forward
   3.1 What is Community-based Rehabilitation?
   Q8 – I know what CBR is
   Q9 – What does CBR mean to you?
   Q20 – What uniquely distinguishes CBR from other strategies?
   3.2 ‘Community-based Rehabilitation’?
   Q21 – Do you think the name of CBR should be changed?
   Q22 – If yes, what should it be changed to?
   Q23 – If no, why should it stay the same?
   Q24 – Other comments regarding the name

The results will be presented at the congress in the above format to provide background information for interactive program sessions and promote discussion about current CBR issues and future directions.
1. Introduction

1.1 Scope

Feedback was obtained through submissions to online survey questions and focus group discussions (FGDS) held across all WHO regions. Opportunities to provide feedback were promoted through the International Disability Development Consortium (IDDC) members and global and regional Community-based Rehabilitation (CBR) networks.

The feedback report summarises findings from PULSE survey responses and FGDs and aims to provide background information to stimulate discussion during interactive sessions of the 2\textsuperscript{nd} CBR World Congress.

A summary of key findings from responses to survey questions and FGDs are presented in three sections relating to the interactive sessions for the Second CBR World Congress. These include:

1. Stakeholders and sustainability
2. CBR in practice
3. The way forward.

1.2 Methodology

\textit{PULSE Survey}

The PULSE Survey, with a total of 24 online survey questions, was promoted through IDDC members and CBR networks to obtain both quantitative feedback and qualitative commentary on current CBR understanding and practice (see Appendix 1 for PULSE survey questions relating to congress sessions). A total number of 256 respondents provided feedback through an online survey software application, Survey Methods. Respondents who answered less than 50\% of the survey questions (excluding demographic data) were excluded from analysis of feedback. The final analysis and summary of findings includes data from 149 survey respondents.

\textit{Focus group discussions [FGDs]}

A total number of 11 FGDs were held across most WHO regions including the Western Pacific (2), African (3), Pan American (2), Eastern (2) and South East Asian (2) with 6-10 participants involved in each discussion.

FGDs were coordinated by the World Health Organisation (WHO) through IDDC members and global CBR networks, who were asked to identify local facilitators. Experience of group facilitators varied and included CBR workers within the network, programme planners, and global advisors. A FGD guide and protocol was provided to facilitators to support the discussion process and reporting of findings.

\textbf{Analysis of Feedback}

\textit{Qualitative data:}

Thematic analysis of FGDs was conducted manually (Braun and Clark 2006) providing a flexible, inductive process of engaging with narratives, seeking out patterns in the data and then organizing them into fluid categories or themes. Qualitative commentary in online survey responses was analysed using NVivo8 software operated by an external research consultant. Respondents’ commentary was coded thematically and word frequency was analysed to reflect qualitative findings.

\textit{Quantitative data:} A summary of quantitative responses from the online survey provided by Survey Methods analysis is presented in bar charts and line graphs for each section. Percentages are used to reflect the spread of responses within each question, due to a varied response rate per question.
1.3 Summary of respondent demographics

**Pulse Survey**

Of the 149 respondents included in the final analysis, 59% were male and 41% were female, and over half were aged between 30 and 50 years old. The large majority of respondents (95%) spoke English and worked in the South East Asian region (SEARO) (70%). Over half of the respondents worked for Non-Government Organizations (NGOs) (60%) and had less than 10 years of work experience (57%).

Minor differences in demographics were found between respondents that were included (n=149) and excluded (n=107) from the final survey analysis, including a slightly greater number of non-English speakers in the excluded group that responded to less than half of the survey questions. See Appendix 2 for a visual representation of responses to demographic questions from both survey respondent groups.

**FGDs**

Approximately 90 people in five WHO regions participated in a total of 11 focus groups. There was an even spread of participants in gender and region. Participants included CBR workers, persons with disabilities, parents of children with disabilities and a few CBR programme managers.

2. Key Findings

Below are the findings categorized into related session themes. PULSE survey results are visually presented in charts and graphs. Participant quotes and key points from focus groups are illustrated in boxes to represent the most commonly occurring themes.

1. Stakeholders & Sustainability

1.1 Sector Responsibility

Q7 - In the country I work CBR falls under the responsibility of (select sector) (n=148)

Almost 70% of survey respondents indicated that the responsibility for CBR falls under the social/welfare (40%) and health (27%) sectors. Focus group participants suggested a need for multi-sectoral responsibility with one sector responsible for coordination of CBR.

- Social: 40%
- Health: 27%
- Education: 13%
- Labour: 5%
- No specific sector: 4%
- Don't know: 2%
- Other: 9%

*‘There is a huge lack of coordination amongst all sectors, including service providers and NGOs’* (FG participant, Bangladesh)

*‘CBR should be a tool to develop a multi-sectoral strategy’* (FG participant, Madagascar)
Persons with disabilities and their families were identified and ranked as the most important stakeholders in CBR in survey responses. This was also mentioned in all FGDs.

*CBR starts from persons with disabilities and their families* (FG participant, Mozambique).

Survey respondents were asked to rank 12 stakeholders from most to least important. Mean ranking scores are illustrated in the graph below. The full list of stakeholders represented in the graph is shown in Table 2 below.

![Mean ranking score vs stakeholders](image)

Table 1: Stakeholders according to rank (highest to lowest level of importance):

<table>
<thead>
<tr>
<th>Rank</th>
<th>Stakeholder</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Persons with disabilities</td>
</tr>
<tr>
<td>2</td>
<td>Families of persons with disabilities</td>
</tr>
<tr>
<td>3</td>
<td>Community support/peer groups</td>
</tr>
<tr>
<td>4</td>
<td>Policy makers at national level</td>
</tr>
<tr>
<td>5</td>
<td>Decision makers at community level</td>
</tr>
<tr>
<td>6</td>
<td>General community members</td>
</tr>
<tr>
<td>7</td>
<td>Government decision makers at provincial/state/regional level</td>
</tr>
<tr>
<td>8</td>
<td>People working as CBR volunteers</td>
</tr>
<tr>
<td>9</td>
<td>Non-government/community</td>
</tr>
<tr>
<td>10</td>
<td>Education and training providers</td>
</tr>
<tr>
<td>11</td>
<td>Healthcare providers</td>
</tr>
<tr>
<td>12</td>
<td>People working as paid CBR staff</td>
</tr>
</tbody>
</table>

Other stakeholders mentioned by respondents (based on response frequency) included faith-based organisations, donor organisations, DPOs, UN agencies, vocational providers, business partners, and the media.

Focus group participants also noted that:

*Persons with disabilities themselves should lead the processes in CBR* (FG participant, Ecuador).
1.3 Challenges for the sustainability of CBR

1.3 Biggest challenges for the sustainability of CBR

**Q17 - The biggest challenges for the sustainability of CBR (n=112)**

The three main challenges for the sustainability for CBR, selected by over a third of online survey respondents, are:

1. Lack of an inclusive approach to policy and practice across sectors (44%)
2. Lack of collaboration with government departments/ministries (34%)
3. Difficulty securing funds (33%).

112 survey respondents selected no more than two biggest challenges. The graph below shows the percentage of respondents that selected the corresponding challenge(s) – See Table 1. *i.e. 33% of the 112 respondents selected ‘3 – Difficulty securing funds’ as one of the biggest challenges.*

Table 2: Challenges for the sustainability of CBR (in order of biggest to smallest challenge):

<table>
<thead>
<tr>
<th></th>
<th>Lack of an inclusive approach to policy and practice across sectors</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Lack of collaboration with government departments/ministries (e.g. health, education, social development etc.)</td>
</tr>
<tr>
<td>3</td>
<td>Difficulty securing funds</td>
</tr>
<tr>
<td>4</td>
<td>Lack of understanding of the concept of CBR by mainstream actors</td>
</tr>
<tr>
<td>5</td>
<td>Lack of ownership by government</td>
</tr>
<tr>
<td>6</td>
<td>Lack of collaboration with civil society organisations involved in community development</td>
</tr>
<tr>
<td>7</td>
<td>Lack of recognition of persons with disabilities as an excluded group</td>
</tr>
<tr>
<td>8</td>
<td>Lack of quality training</td>
</tr>
<tr>
<td>9</td>
<td>Lack of clearly identified cadre of workers</td>
</tr>
</tbody>
</table>

Focus group participants agreed that funding and lack of local government involvement are major challenges to sustainability of CBR

*‘More funds need to be allocated to CBR’ (FG participant, Egypt).*
They also indicated a greater need for community knowledge and ownership of CBR programs for sustainability.

'It is the local governments that need to be empowered to drive CBR and to make it sustainable’ (FG participant, Ecuador).

69% of all survey respondents said that international NGOs and other out of country funding financially resources their work.

Focus group participants indicated that:

‘Most programs are largely dependent on donor funding and have limited sustainability strategies (and that) any challenges experienced in the donor countries and those experienced by the individual donors automatically affects operations’ (FG participant, Uganda).
2. CBR in practice

2.1 CBR training

Q10 – What I know of CBR I know from... (n=149)

Just over half of respondents have received formal CBR training (53%) while 47% have received no formal training. The chart above represents the methods respondents who did not receive any formal training (47%) used to acquire knowledge about CBR principles and practice. Comments were made that the main method of learning CBR is through practice, alongside other methods.

Only 5% of respondents said they received all of their CBR knowledge through formal training alone. The majority of those that received formal training also gained knowledge about CBR through other methods, including; learning from other through conferences/congresses; discussion with other people; reading documents (websites/books) and; learning by doing.
2.2 Barriers to implementation

Q11 - What is the biggest barrier to the implementation of CBR? (n=114)

The three main barriers to CBR implementation, selected by over 30% of online survey respondents, are:

1. Lack of funding (44%)
2. Lack of awareness/knowledge in mainstream sectors and organisations (34%)
3. No involvement of government (30%).

114 survey respondents selected no more than three barriers. The graph below shows the percentage of respondents that selected the corresponding challenge(s) – See Table 2. I.e. 30% of the 114 respondents selected ‘3 – no involvement of government’ as one of the biggest barriers.

Other methods of training identified by a few respondents include; from persons with disabilities; direct involvement with communities; and schools.

Focus group participants agreed that there is a lack of training opportunities, especially in the areas of management, empowerment and advocacy.
Table 3: Barriers to implementation (biggest to smallest):

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lack of funding</td>
</tr>
<tr>
<td>2</td>
<td>Lack of awareness/knowledge in mainstream sectors and organisations</td>
</tr>
<tr>
<td>3</td>
<td>No involvement of government</td>
</tr>
<tr>
<td>4</td>
<td>Attitude(s) of local government departments</td>
</tr>
<tr>
<td>5</td>
<td>Lack of recognition of the specific needs to people with disabilities</td>
</tr>
<tr>
<td>6</td>
<td>Lack of clarity about what CBR is</td>
</tr>
<tr>
<td>7</td>
<td>Lack of training for CBR workers/volunteers/field staff</td>
</tr>
<tr>
<td>8</td>
<td>Attitude of health and education professionals</td>
</tr>
<tr>
<td>9</td>
<td>Lack of capacity of CBR personnel to do the work expected</td>
</tr>
<tr>
<td>10</td>
<td>There is no specific cadre of people to do the CBR work</td>
</tr>
<tr>
<td>11</td>
<td>Lack of training for managers</td>
</tr>
<tr>
<td>12</td>
<td>Lack of clarity of the roles &amp; responsibilities of CBR workers</td>
</tr>
<tr>
<td>13</td>
<td>No involvement of NGOs</td>
</tr>
</tbody>
</table>

Other individual responses included lack of ownership of CBR by the community, attitudes of persons with disabilities, lack of (staff) motivation and poor collaboration/partnerships across sectors and with government.

2.3 Career development

**Q14 - There is an opportunity for people to make a career for themselves in CBR (n=147)**

70% of survey respondents agree (24% strongly agree, 46% agree) with the statement that there is an opportunity for people to make a career for themselves in CBR.

- Strongly Agree: 24%
- Agree: 46%
- Neutral: 16%
- Disagree: 5%
- Strongly disagree: 8%

**Q16 - There should be a professional association that represents people working in CBR (n=149)**

A large majority (76%) of survey respondents agree (35% strongly agree, 41% agree) with the statement that there should be a professional association that represents people working in CBR.

61
2.4 Curriculum development

**Q15 - There is a need to develop a global curriculum for CBR (n=149)**

Approximately 80% of respondents agree or strongly agree that there is a need to develop a global curriculum for CBR. However, focus group participants held differing opinions on the need for a global curriculum.

Some focus group participants agreed that there should be certified CBR professionals.

> ‘A new cadre of generic CBR workers is needed. This will give CBR as such more accreditation’ (FG participant, Colombia).

They also expressed that a global curriculum should include generic CBR training that can be adapted locally with specialized modules.

> ‘A generic approach, which can be adapted locally. The CBR workers need a certificate that is nationally recognized’ (FG participant, Mozambique).

> ‘If a University or formal training institution would take over the training of CBR personnel, the work would become institutionalized and transform into a very technical work which would be taken on by a few only’ (FG participant, Ecuador).
2.5 Research in practice

**Q19 - Do you make use of research results in your day-to-day work? (n=136)**

Almost 70% of survey respondents state that they occasionally (35%) or frequently (34%) make use of research results in their daily work. 20% of respondents never, very rarely or rarely make use of research in practice.

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>1%</td>
</tr>
<tr>
<td>Very rarely</td>
<td>8%</td>
</tr>
<tr>
<td>Rarely</td>
<td>11%</td>
</tr>
<tr>
<td>Occasionally</td>
<td>35%</td>
</tr>
<tr>
<td>Frequently</td>
<td>34%</td>
</tr>
<tr>
<td>Very frequently</td>
<td>11%</td>
</tr>
</tbody>
</table>

3. The way forward

3.1 What is Community-based Rehabilitation (CBR)?

**Q8 - I know what CBR is (n=146)**

99% of survey respondents state that they know what CBR is.

<table>
<thead>
<tr>
<th>Answer</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>99%</td>
</tr>
<tr>
<td>No</td>
<td>1%</td>
</tr>
</tbody>
</table>

**Q20 - What uniquely distinguishes CBR from other strategies? (n=114)**

Over 30% of online survey respondents indicated that the following factors most uniquely distinguish CBR from other strategies:

1. CBR focuses specifically on inclusion of people with disabilities in community services and activities
2. CBR is community-based
3. CBR is about inclusive development
114 survey respondents selected no more than three distinguishing factors. The graph below shows the percentage of respondents that selected the corresponding distinguishing factor(s) - See Table 3. I.e. 30% of the 114 respondents selected ‘3 – no involvement of government’ as one of the biggest barriers.

![Graph showing percentage of respondents selecting distinguishing factors]

Table 4: CBR distinguishing factors (highest-to-lowest based on frequency of selection):

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Focuses specifically on inclusion of people with disabilities in community services and activities</td>
</tr>
<tr>
<td>2</td>
<td>Community-based</td>
</tr>
<tr>
<td>3</td>
<td>Inclusive development</td>
</tr>
<tr>
<td>4</td>
<td>Priorities of people with disabilities</td>
</tr>
<tr>
<td>5</td>
<td>Empowerment</td>
</tr>
<tr>
<td>6</td>
<td>Rehabilitation</td>
</tr>
<tr>
<td>7</td>
<td>Community development</td>
</tr>
<tr>
<td>8</td>
<td>Poverty reduction</td>
</tr>
<tr>
<td>9</td>
<td>Human rights</td>
</tr>
<tr>
<td>10</td>
<td>Education</td>
</tr>
</tbody>
</table>

Focus group participants, however, demonstrated a great variation in their understanding of CBR. Their level of understanding depended on sociocultural context, geographical region, local projects and initiatives.

Some participants admitted to having a limited understanding of CBR:

“What I am asking myself is: What is not CBR? I don’t know actually” (FG participant, Colombia).

Focus group participants also indicated that there is particularly a lack of understanding about CBR in the communities.

“Some people in the communities work using CBR approaches and have never heard about it and never seen the guidelines, and they are doing good work...” (FG participant, Uganda).
Q9 - What does CBR mean to you? (n=127)

The word cloud below was generated based on relevant word frequency in answers provided by 127 respondents.

Word frequency is represented by the size of the word. Terms including ‘persons with disabilities,’ ‘community,’ ‘inclusion’ ‘development,’ ‘empowering,’ ‘social’ and ‘strategy’ were among the most frequently used terms to describe what CBR means to respondents.

3.2 ‘Community-based Rehabilitation’?

Q21 - Do you think the name of CBR should be changed? (n=137)

Opinions are divided within regions and countries about whether the name ‘Community-based rehabilitation’ or ‘CBR’ should be changed. Approximately two-thirds of survey respondents (71%) think the name should not be changed while the small majority of focus group participants are in favour of a name change.
Q22 - If yes, what should it be changed to? (n=35)
17 of 36 (49%) respondents to Q22 (‘If yes, what should it be changed to?’) answered with ‘Community-Based Inclusive Development’ or ‘CBID.’
Community-based Inclusive Development (CBID)
Community-based inclusive approach (CBIA)
Community-based service
Community-based disability inclusion
Community-based inclusion
Community-based inclusive disability
Community-based interventions
Community-based rehabilitation and inclusive development
Community development and rehabilitation
Community-led rehabilitation
Community support services
Community Rehabilitation service
Count me in
Comunidades de aprendizajes
Disability Mainstreaming Programme
Inclusive community development
Inclusive development for sustainable growth
Inclusive development programme
RBR – Rights-based rehabilitation
Village-based rehabilitation

Focus group participants indicated that this name ‘CBID’ is already being used in some countries.

‘CBID is a good name because it creates more opportunities for inclusive set up in public and in the private sector’ (FG participant, India)

‘The change of name (to CBID) has helped a lot to involve DPOs and local governments. Additionally the families understand it is not only rehabilitation that is needed’ (FG participant, Ecuador).

Other individual responses included ‘Inclusive Community Development (ICD),’ ‘Community-based Inclusion (CBI)’ and ‘Community-based Disability-Inclusive Development (CBDID).

Q23 - If no, why should it stay the same? (n=71)
The following themes extracted from responses are presented from the most-to-least commonly occurring:

Widely known:
The current name ‘CBR’ is widely known, accepted, recognised and practised in many languages and communities. Respondents noted that it is important to maintain the ‘CBR’ brand that has been established in many contexts and languages.

Accurately and clearly defines CBR activities:
Survey respondents expressed the idea that the current name accurately and fully defines the CBR concept and activities. They note that the name is easily understood, adequate, appropriate, comprehensive, self-explanatory, clear and succinct.
Risks associated with a name change:
Survey respondents and focus group participants identified a number of risks associated with changing the name. They particularly noted that it might cause confusion because “CBR is widely known” (FG participant, Bangladesh) and that there is a risk of having to reintroduce the concept and restart the process of raising awareness.

Focus group participants noted that a clear explanation of the new name will be just as necessary as it is for ‘CBR.’

“This name is not the confusing, it depends on how you explain it. You can give it another name, but you are still going to explain another name” (FG participant, Mozambique).

Survey respondents also indicated that significant time and costs would need to be invested to change the name and reeducating people.

Other:
Other respondents stated that changing the name is not important, and that attitudes and what CBR implies is most important. It was also noted that the current name is unique, not stigmatising, and easily distinguished from other programs.

Q24 - If yes, why should it be changed? (n=71)

The following themes (presented below from most-to-least commonly occurring) were extracted from other comments regarding the name (Q24).

Rehabilitation’ is misleading:
Many survey respondents and focus group participants in favour of a name change note that the name needs to change to reflect better the program concept, aims and activities.

It was particularly emphasised that using the term ‘rehabilitation’ in the title is misleading. They stated that factors that make the program unique such as inclusion, development, equity and empowerment (and not only rehabilitation) need to be reflected in the name.

“The word development better describes what we are doing.” (FG participant, Madagascar)

One survey respondent noted that the name limits workers to practicing rehabilitation while the program focuses much more on inclusion. They also note that reference to ‘rehabilitation’ is confusing for many stakeholders who are not working in the CBR or disability field.

Recognition and funding:
Focus group participants note that a name change that better reflects the program concept may lead to appropriate recognition of program activities and increased support and funding.

“It is important how outsiders think about this and how it will affect them. This can affect support and funding” (FG participant, Egypt).
Other:
Other comments were made that the current name is too technical. Another comment was made that the main stakeholders (persons with disabilities) do not agree with the current name.

Strengths & limitations

The sample of survey respondents and focus group participants does not accurately represent those using CBR in practice throughout the world. It is also particularly biased toward CBR experiences in the South-East Asia region.

Not all respondents completed every survey question and a large number only completed the demographic data. A low response rate to survey questions was minimised by excluding respondents who answered less than 50% of questions 7-24 (excluding demographic data).

Due to time constraints, focus groups were coordinated by local facilitators with varying levels of experience in focus group facilitation and reporting. Facilitator and participant demographic data is incomplete, which questions representation of data and level of bias. Protocols were provided to facilitators to control for reliability and validity; however, significant variation in focus group processes and reporting were noted.

Appendix 1: PULSE Survey questions

DEMOGRAPHIC INFORMATION
Q1 – What language do you speak?
Q2 – Please select your gender
Q3 – Please select your age
Q4 – Please select the number of years of working experience you have in the field of CBR
Q5 – Please select the region where you predominately work?
Q6 – What is your (primary) working position?

STAKEHOLDERS AND SUSTAINABILITY
Q7 – In the country I work CBR falls under the responsibility of the: (select sector)
Q12 – Rank the following CBR stakeholders according to their importance, 1 (most important) to 12 (least important)
Q13 – Is there any other important stakeholder(s) not mentioned above?
Q17 – The biggest challenges for the sustainability of CBR are? Choose two barriers
Q18 – What are the sources of financial resources for your work?

CBR IN PRACTICE
Q10 – What I know about CBR I know from (select all that apply)
Q11 – What is the biggest barrier to the implementation of CBR? (choose up to two options)
Q14 – There is an opportunity for people to make a career for themselves in CBR
Q15 – There is a need to develop a global curriculum for CBR
Q16 – There should be a professional association that represents people working in CBR
Q19 – Do you make use of research results in your day to day work?

THE WAY FORWARD
Q8 – I know what CBR is
Q9 – What does CBR mean to you? Please specify in max. 50 words
Q20 – What uniquely distinguishes CBR from other strategies? Select two terms
Q21 – Do you think the name of CBR should be changed?
Q22 – If yes, what should it be changed to?
Q23 – If no, why should it stay the same?
Q24 – Other comments regarding the name (If yes, why should it be changed)
Appendix 1: Pulse Survey respondents: demographics (Q1 - Q6)

**Number of respondents**

| Group 1: Respondents INCLUDED in analysis (>50% of responses completed*) | 149 (blue) |
| Group 2: Respondents EXCLUDED from analysis (<50% of responses completed*) | 107 (light blue) |
| TOTAL NUMBER OF RESPONDENTS | 256 |

*Excluding demographic data.

**Gender**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>59%</td>
</tr>
<tr>
<td>Female</td>
<td>41%</td>
</tr>
</tbody>
</table>

**Age**

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Under 30</td>
<td>11%</td>
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<tr>
<td>30-39</td>
<td>27%</td>
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<tr>
<td>40-49</td>
<td>28%</td>
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<tr>
<td>50-59</td>
<td>21%</td>
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<tr>
<td>60+</td>
<td>13%</td>
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**Language spoken**

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<thead>
<tr>
<th>Region of war</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>SEARO (South-East Asian)</td>
<td>70%</td>
</tr>
<tr>
<td>AMRO (The Americas)</td>
<td>4%</td>
</tr>
<tr>
<td>EURO (European)</td>
<td>3%</td>
</tr>
<tr>
<td>EMRO (Eastern)</td>
<td>6%</td>
</tr>
<tr>
<td>AFRO (African)</td>
<td>14%</td>
</tr>
<tr>
<td>Global</td>
<td>8%</td>
</tr>
<tr>
<td>WPRO (Western Pacific)</td>
<td>0%</td>
</tr>
</tbody>
</table>

**Region of war**

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<td>8%</td>
</tr>
<tr>
<td>WPRO (Western Pacific)</td>
<td>0%</td>
</tr>
</tbody>
</table>

**Working position**

<table>
<thead>
<tr>
<th>Years of work experience</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>64%</td>
<td>70%</td>
</tr>
<tr>
<td>6%</td>
<td>14%</td>
</tr>
<tr>
<td>2%</td>
<td>8%</td>
</tr>
<tr>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>1%</td>
<td>6%</td>
</tr>
</tbody>
</table>
Government 9%
  10%

INGO 11%
  7%

NGO 49%
  59%

DPO 15%
  16%

Academia 9%
  6%

Other 7%
  2%

END