

## **VOICES FROM THE FIELD**

### **Critical reflections on the usefulness of the 3<sup>rd</sup> Regional Conference on Community based Rehabilitation (CBR) in the Americas in Medellin**

Joerg Weber<sup>a\*</sup>

*<sup>a</sup>London School of Hygiene and Tropical Medicine. Corresponding Author- Email: Joerg.G.Weber@lshtm.ac.uk*

#### **Background on CBR**

CBR is promoted by WHO/UNESCO/ILO as the intervention of choice to promote Disability inclusive Development. When first implemented in the 1980s, CBR addressed mainly the health and impairment focused needs of Persons with Disabilities at a non-specialist level within communities. The current understanding of disability is that it is an evolving concept and experience, as noted in the UN Convention on the Rights of Persons with Disabilities (CRPD). Therefore there is increased recognition of Persons with Disabilities as an active and resourceful part of their communities rather than a vulnerable group of society and recipients of medical rehabilitation. Perspectives such as these have been influenced by shifts in discourse such as the turn towards the social model of disability in the global North. In parallel, CBR has undergone major re-conceptualisations, and is now, in theory, a multi-sectorial and participatory strategy which is implemented in the community using predominantly local resources. However, critical evaluations of CBR in practice remain seriously lacking, as do clear understandings of what CBR actually means and is intended to achieve in practice. This short reflective piece does not aim to and cannot possibly fill this space. Instead, it reflects critically and in retrospect on the experience of the CBR congress in 2013 in Colombia (<http://www.3ercongresocontinentalderbc.com>). In this paper I build on the premise that a conference should be judged by its utility and the actual use of the conference proceedings and outcomes. Therefore any conference organising body should facilitate the design and process of such an event with careful consideration of how everything that will be done, from beginning to end, will affect use and outcomes. I start off by providing a background of the CBR conferences and that of Medellin, and will then move on to critically explore notions of usefulness drawing a few conclusions as I attempt to answer the question: Was the conference useful?

## **CBR Conferences**

As has become customary in many areas of international development, the introduction and rolling out of concepts and ideas to the wider audience goes hand in hand with bringing together practitioners, experts and potential donors by regularly organising conferences. One, though, must be excused for sometimes sitting back and wondering about the validity and importantly, contribution of these conferences.

Under the patronage of the World Health Organisation (WHO) eight regional CBR conferences and one world congress have been organised since 2005. Latin America is at its third regional conference, the latest held in Medellin, Colombia between October 23rd and 25th 2013. I have not attended each and every CBR conference, so will be using this recent experience to reflect on some issues.

According to the conference organizers, about 800 participants from 20 countries took part in one or more of the various sessions of this event. As it is common practice, the 'official' conference programme consisting of presentations and speeches as well as a few panel discussions, was accompanied by various side meetings and social events.

It became obvious from the first morning that the choice of the conference venue was not a good one. Given the type and number of participants attending, the size of the location as well as the accompanying needs of accessibility or the need to provide separate meeting rooms, was not dealt with adequately by the organisers. The venue was far too small for the number of people attending, and mobility was seriously constrained for persons with a disability. A striking feature of the conference was the fact that during breaks, numerous groups of participants had to struggle to find a reasonably quiet place for side meetings. This often resulted in situations where meetings were held between doors and in some corner of the place, with people having to sit on the floor. Surely, this cannot be called an enabling and accessible environment for persons with disabilities.

This lack of purposeful action to prepare the event for the participation of persons with disabilities became even more obvious by the fact that there was no information material provided in Braille at the venue. The images displayed on the stage of the conference room showed pictures of white and well-nourished persons with predictable and moderate impairments, most typically children with downs syndrome. These images could well have been used as a high-gloss blueprint for a charity fundraiser of a cosmopolitan service club, collecting funds for further expansion of the Rehabilitation Unit in a private hospital and definitely not a rights-based conference. They surely neither represent the social reality that can be observed in CBR programmes nor do these charity driven images do justice to the

perception of persons with disabilities as resourceful members of their communities. One wonders whether this lack of awareness and coordination was partly due to the obviously poor flow of information between the academic conference committee and the *Red de las Americas*, the continental CBR network.

The conference organisation was handed over to the municipality of Medellin which, it appears, used the event as a stage for political promotion, capitalized on by politicians to highlight local processes and what they deem are advances in the field of rehabilitation in their city.

### **What is a useful CBR conference?**

In order to find a working definition of what should be considered a ‘useful’ conference, it is helpful to look at objectives of success set by the organizing committees of previous CBR conferences. The aim of such a conference as stated by the organizers of the regional CBR conference in Bangkok in 2009 is ‘to promote and strengthen CBR across the region and globally; and to mobilize and support resources and information exchange’ (<http://www.cbrasiapacific.net/>). The authors of these objectives differentiate between:

- a) Outcomes creating a positive public perception about CBR (CBR external)
- b) Outcomes leading to better informed, motivated and therefore more efficient CBR stakeholders and practitioners (CBR internal)

The organising committee in Medellin adapted the same type of differentiation, additionally linking internal exchange, learning and networking to the successful external representation of CBR. Better representation leads in their interpretation, to emerging possibilities to more efficiently influence national politics towards more inclusive development practice: ‘..To identify by means of exchange and collective review the lessons learned about CBR and to use them as reference to influence national policies for inclusive development...’ (<http://www.3ercongresocontinentalderbc.com/>).

It is clear therefore that it is often the organisers themselves who frame and translate the abstract construct of ‘useful’, give shape to it, and identify the standards that should be used to answer the question: Was the conference useful?

Consequently it can be inferred that a ‘useful’ CBR conference should provide positive outcomes on two levels:

- At a personal and group level ('useful' for participants): Deeper knowledge about CBR and feeling of increased commitment to CBR principles
- At a conceptual level ('useful' to enhance the CBR concept): Successful advocacy of CBR principles and values to the society generally and more particularly to potential external collaborators and partners

### **“Useful” for Participants**

It is beyond the scope of this paper, and also impossible, to explore in detail what exactly participants have learnt during this conference and whether they show after the conference an enhanced belief in the effectiveness of CBR as an efficient facilitator of change. These questions cannot be answered by using standard evaluation templates about programme content, speakers' abilities and conference logistics. Instead, a carefully developed pre conference -post conference evaluation is needed, in particular one providing the space and freedom for participants to articulate whether the conference was useful for them, honestly and without fear.

After nine CBR conferences worldwide, one must truly wonder why none of the organising teams so far has done such an evaluation. It would be reasonable to assume that practice-based learning promoted by the most cited reference at CBR conferences, the CBR guidelines, is also being used to learn from similar past events and to disseminate these findings to the wider CBR community.

To build participant-based feedback loops into the loose system of regional conferences would not only help the organizers to reflect on the usefulness and ultimately the success of each conference, but would also assist to improve the effectiveness of subsequent conferences as well as to follow up the thematic continuum between these conferences. Hence, subsequent CBR conferences should not be merely successive, thematically isolated events, moving every few years to a different location. Rather they should aim to be integrated and thematically interconnected in a system of regional conferences that allows feedback adjustment and self-correction by looking at the difference between actual and desired results.

The presentations and discussions of past CBR conferences in Africa and the Asia Pacific region have been documented and published as books or as strings of articles. These publications do not represent comprehensive evaluations of the respective conferences, nor do they reflect the voices and narratives of disabled people and CBR workers to the desirable extent dictated by the topic. They are rather a summary and continuation of discussions that happened at and around the conferences. Nevertheless, these papers are a step towards establishing feedback loops and to thematically link subsequent regional CBR conferences. It

is not clear why a similar initiative has not been followed through so far in the Americas. What remains from the conference in Medellin 2013 (as well as the two preceding regional CBR conferences in Chile and Mexico) is a webpage with little information and almost no self-reflection.

### **Useful for enhancing the CBR concept**

Having excluded a closer examination of ‘usefulness for participants’ from this reflective paper, the question remains how useful the conference was to create a positive image of CBR. Surely, to answer this question the conference organizers must be evaluated by the very same principles they want to promulgate through the conference. One of the key principles of CBR is the *active participation of persons with disabilities in all spheres of planning and implementation*. The recommendations of recent international frameworks on disability such as the UN Convention on the Rights of Persons with Disabilities (CRPD) and the World Report on Disability (WHO/ World Bank 2011), define participation of persons with disabilities in political and public life as a human right as well as an important step towards other human rights. It encompasses the right to vote and the right to be elected. Chambers (2012) broadens this definition by pointing out that ‘participation has implications for power relations...attitudes and behaviour’. This means that participation goes beyond the formal recognition of democratic processes towards control of these processes, notably the right to participate in decision making. The CRPD outlines the latter aspect quite clear in its preamble: ‘Considering that persons with disabilities should have the opportunity to be actually involved in decision – making processes about policies and programmes, including those directly concerning them’ (UN 2006: p.1). The CBR guidelines follow along the same lines by encouraging the CBR stakeholders to “facilitate the empowerment of persons with disabilities and their families by promoting their inclusion and participation in development and decision making processes’ (2010: p.12). The document goes on to state how: ‘One of the key threads running through all CBR programmes is participation - all key stakeholders, particularly people with disabilities and their family members, are actively involved at all stages of the management cycle’ (WHO 2010: p.42).

It can therefore be concluded that a main indicator for successfully advocating CBR principles is that the CBR community itself must demonstrate that it does actively involve persons with disabilities in planning and decision making in all areas and at all levels of CBR. This includes the planning and implementation of a CBR conference. One might think that the apparently basic precondition of empowering persons with disabilities to be decision makers on their own behalf should have been reflected in all processes and at all stages of planning and organizing the CBR conference in Medellin, namely through:

- Active participation of persons with disabilities in conference planning processes
- Active participation of persons with disabilities as presenters, panel members and speakers during the congress

A closer look at the list of individuals forming part of the planning committee reveals that persons with disabilities were disproportionately under-represented. The same impression is created when going through the list of names of the academic conference committee. The suspicion arises that the inclusion of persons with disabilities in the planning bodies, and their voices in the decision making processes prior to the event were not regarded a priority. This impression is reinforced by looking more closely at issues of participation during the congress itself. Although a few persons with disabilities were presenting in some of the concurrent sessions, they were practically absent in the list of panel members and speakers. These were largely composed of academics, politicians and high level organizational staff, and much of the discourse revolved around how 'good' CBR is, how all is going well in their respective areas and projects, and how to keep on moving on the same road. Instead, problems and difficult themes such as poverty, social justice or psychosocial issues, to name a few, were completely absent, and the real concerns of staff on the ground were flagrantly ignored. Presentations presented recommendations without any empirical work, or evaluation, and one was left wondering what the sources of information were.

But, most critically, the voices of disabled people remained notoriously absent, almost stifled in this conference *of* and *for* the non-disabled. Spaces for questions and reflections were not available, which meant that there were no critical spaces for reflection, disagreement, and importantly debate. This stifled any notion of genuine participation but also ownership of the conference by persons with a disability. Instead, many resorted to mumbling disagreements and discontent with the content of the speakers to each other, echoing frustration and sometimes anger by people who were confined and forced to sit down, listen, nod and applaud. This frustration is understandable when many have travelled long distances expecting to discuss in open spaces for reflection and collaboration and to look at ways forward with enhanced insight. But this was far from the reality.

And resistance did become evident. If any further proof was needed that the organizing team of the conference had in practice neglected the very core values of CBR, namely the inclusion of persons with disabilities in all decision making processes, then this proof was to be found in day two of the conference. In this instance, a spontaneous initiative led by people with disabilities was launched to have a meeting parallel to the regular programme in order to express discontent with the proceedings of this conference and to discuss recommendations and action points to improve the participation of persons with disabilities in future conferences. This meeting was organized only in a few hours, allowed only persons with

disabilities, and word spread only by word of mouth. In a crowded room, and with little or no leadership, people talked, and each came with their own baggage and feelings about the conference. That there was disgruntlement was more than evident in coffee breaks and in times surrounding the conferences. The number of people lingering outside was also a clear testimony that there was much about the content and structure that was not in place and was far from what people were expecting. In this impromptu meeting, it was also evident that some of the organizers were far from happy, and were extremely suspicious, witness in one instance where a government person snuck in to spy on what was happening.

The resulting document from this meeting was then read by members of this group at the closing ceremony following the presentation of the ‘official’ conference manifesto. While the point of the lack of participation was clearly articulated, I felt that much of the strength of the original message was unfortunately drowned in an excessively diplomatic message that the organizers even failed to hear. Still, the 3<sup>rd</sup> regional conference CBR in Medellin remains the first of its kind that has closed with the reading of two parallel action plans: one rather brief ‘official’ manifesto dominated by generalities and one developed by the principal stakeholders of CBR, the persons with disabilities, strongly advocating for better inclusion in congress planning and implementation.

But, it is not only the fact that two separate manifestos were presented, that is deeply disturbing, but the realization that persons with disabilities had, in order to be heard, to resort to the means of organizing a parallel session at an event they should actually have been owning from start to finish. The question whether the CBR conference in Medellin has been successful in advocating one fundamental value of CBR, namely participation of persons with disabilities, can conclusively be answered in the negative. The most distinct argument pointing to the failure of the conference organization body to comply with its self-established standards is the manifesto of persons with disabilities read at the closing of the Medellin CBR conference. Below is the unabridged wording of the recommendations arising from discussions about principles of inclusion and decision making:

Recommendations of the Disabled Persons’ Action Committee (3rd Continental CBR Conference in Medellin):

- a. To ensure the accessibility to information and communication for persons with disabilities at conferences and other events.
- b. To ensure that persons with disabilities will have in future events have full access to buildings, to the environment, to transport facilities as well as to trained support staff.

- c. To ensure that the CBR congresses, provide space for dialogue between people with disabilities, the general population, international agencies and governments.
- d. To promote the signature and ratification of the CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES and its Optional Protocol in countries on the continent that have not yet signed.

The present statement confirms that disabled participants must become key players in the implementation of CBR.

But if this message will be heard or not is yet to be seen, not least because the sector remains dominated by non-disabled people, their voices and priorities.

## **Conclusion**

As I reflect on what makes a useful CBR conference, one important dimension is perhaps that it has to meet expectations from the point of view of the attendees. Since every participant brings a unique set of interests, needs, knowledge and experience to this event, it is important to ask for feedback on factors relating to any disjunction between the conference as planned and advertised and the conference as delivered. This information is not only needed to develop a view of the value of the event but the knowledge gained is useful to plan other conferences and raise the bar of knowledge for future events.

Additionally the results of such an evaluation should be disseminated in open and accessible formats, leaving room for follow up discussions.

Giving evidence of the usefulness for the participants is one aspect of a critical reflection that should be an intrinsic part of every CBR conference.

Another equally important aspect should be to continuously evaluate whether all actions and activities connected to organising, implementing and following up a CBR conference reflect the values of the CRPD and the CBR guidelines, especially in regards to participation and inclusion of persons with disabilities at all stages and levels of conference planning and management. And at other moments it may also be useful to question the validity of the guidelines themselves.

A CBR conference planning committee has the positive obligation to promote an enabling environment. This means that its members are duty bound to guarantee, through the adoption



of positive measures, that persons with disabilities have the actual opportunity to exercise their right to decision making. The organisers of the Medellin conference have completely failed in addressing this issue. The baton has been handed over. Ecuador was chosen as host of the 4<sup>th</sup> CBR Continental Conference in 2016.

All that remains is to express the hope that the organizers of the conference in Ecuador have listened to the voices of persons with disabilities and seize the opportunity to organize a truly inclusive event where persons with disabilities are the key stakeholders.

### **References**

Chambers R. (2012). Participation for Development: A Good time to be alive? Keynote address at the Australian Council for International Development (ACFID) conference in Canberra on 28<sup>th</sup> November 2012.

United Nations (2006). *Convention on the Rights of Persons with Disabilities*. New York: UN

WHO/World Bank (2011). *World Report on Disability*. Geneva: WHO and World Bank.

WHO/ILO/UNESCO (2010). *CBR Guidelines*. Geneva: WHO