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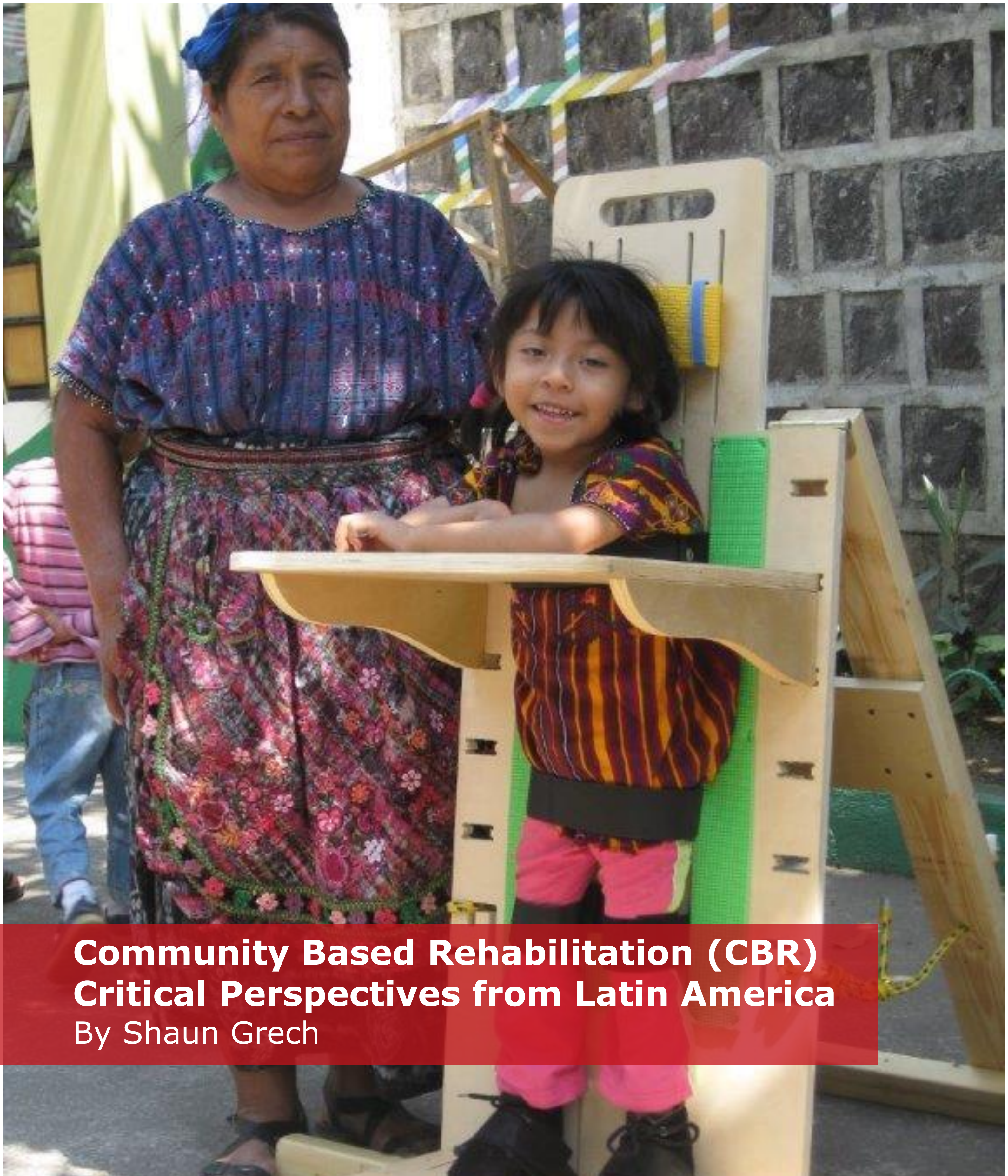

Community Based Rehabilitation (CBR) Critical Perspectives from Latin America

By Shaun Grech

Acknowledgements

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Author:
Shaun Grech
The Critical Institute, Malta
www.criticalinstitute.org
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1. Executive Summary

This study initiated from exchanges between the author (Grech) and CBM in 2013, following a successful narrative workshop held the same year. The workshop, run by Grech a day before the Latin American CBR congress in Colombia brought together various Latin American CBR colleagues and partners to discuss, share and learn in a safe but critical space, where narrative was the key focus. Apart from the enthusiasm generated in this workshop, we were struck by how much participants (all involved in CBR) felt the need to share their own narratives, discuss and debate, and importantly to reflect critically on key conceptual issues, their own work, their experiences, and CBR more broadly.

As we set out to follow this up, perfectly aware that Latin American perspectives are still rarely heard, we considered that prioritising stories, perceptions, critical thought and priorities, especially of those working on the ground had to take centre stage. We also wanted to articulate and present these reflections, alongside chunks of narrative and some visual material in a brief report with some analysis- a learning experience in its own right. Our role as 'outsiders', we agreed, was simply that of listening and learning while working as partners and allies. To share, speak and discuss we set up an online platform, a Google Group, but later decided to extend from the Colombia workshop and make the most of group work in person. We held three focus groups/workshops in Nicaragua, Guatemala and El Salvador, a choice determined by the small budget we had to work with, and logistical convenience. In these day-long groups facilitated by Grech, we openly talked, discussed, expressed ideas, including problems, gaps, and potential 'solutions' around various areas of CBR, including discourse and practice. Using a fluid guideline, we tried to reach out to other places, so two colleagues (Gonna Rota and Katharina Pfortner) tied in a chat around issues of CBR discourse and practice, and motivated others to send us some material using seminars and meetings in Honduras and Peru.

This report presents some of these reflections, among other issues. These are not the voices of all Latin American CBR workers. Far from it. It also does not claim or intend to represent or generalise. It is but one small (and admittedly partial) effort at listening to and presenting some voices, views and perspectives that are seldom heard by outsiders, and to learn from these.

2. Short Introduction

The World Report on Disability (WHO and World Bank) has recently estimated that around 15% of the world's population has some type of disability and the majority of this population is located in the global South. The interactions between poverty and disability have been recognised in recent years (see Groce et al. 2011; Grech, 2015), with many suggesting that persons with disabilities encounter barriers in a range of spheres, including health and rehabilitation, education and work. As a result, many remain among the poorest of the poor in their respective contexts. Part of this situation may be also attributable to the fact that disability has, until very recently, been excluded from development policy, practice and research (Grech, 2011).

Community Based Rehabilitation (CBR) has over the past decades become a staple in discourse referring to disability in the global South. Conceptualised and framed by the WHO and later promoted by organisations such as CBM and others including the International Disability and Development Consortium (http://www.iddcconsortium.net/), it quickly became a powerful discursive and practical tool for addressing rehabilitation and other needs. Motivated by the principles of cost-effectiveness, participation, local sourcing of resources, and importantly effective inclusion of family and community (see http://www.who.int/disabilities/cbr/en/), it persists as a perceived gold standard for understanding and working on disability in the global South. Over the years we have seen the development of CBR guidelines and matrices, conferences on the subject, and training. Importantly, CBR has been married to other growing trends and fashions in the sector including those of Disability-inclusive development (DID) (see www.asksource.info and the former Asia Pacific Disability Rehabilitation Journal, recently renamed 'Disability, CBR and Inclusive Development' (DCID). CBM too recently published its own toolkit on DID (see CBM, 2015).

While CBR has grown as a notion and practice in the small but burgeoning field of disability and development, it also true that much of this exponential growth has been accompanied by little critical reflection on CBR in academic, but also practice circles. This includes a lack of critical thought on its tenets and practices, and as some have expressed, there is still sparse or no critical evaluation of its effectiveness, impact, and relevance in practice (see Miles, 2000; Grech, 2009; Finkenflugel et al. 2005; Kuipers et al. 2015). CBR is celebrated, but spaces for reflection, for questioning, especially by local people working within it, remain, as it seems, very few. One may speculate that this may be because of fear of compromising funding, or of challenging established discourse. But it may also be because many of those engaged in CBR practice may find little time or opportunity for such reflective exercises. There are also strong informational bottlenecks, that is that literature that is produced, for example in regions such as Latin America, rarely finds its way to readers in other geopolitical areas, especially the global North, whether for linguistic, dissemination, power or other reasons. Conversely, that produced in the global North may seldom be read by those in the global South.

The growth of CBR discourse, and to an extent formalised practice over the past decades, has largely happened in the Asia Pacific region and Africa, with networks shaping up within these regions. But CBR (known as *Rehabilitación basada en la comunidad (RBC)* has also been expanding in the Latin American context in recent years, largely as a formal programme and strategy[1]. Support, promotion and perhaps

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[1] It is important to note that CBR, variants or alternative models of this, were in fact developing on their own accord over the past decades in countries such as Chile, Argentina, Colombia, Nicaragua, Mexico and Honduras. Some developed from and also in reaction to more medical

introduction of this concept have been heavily instigated by international stakeholders such as CBM. Nevertheless, local and regional interest continues on the rise. Networks ('redes') of programme managers, academics and others continue to form around CBR, to discuss and promote this ideology and/or practice, and also to publish material, including lessons learnt (see for example http://www.snr.gob.ar/uploads/RBC-Lec-LeccionesAprendidasOPS.pdf).

Despite these movements, though, it is no secret that internationally, the voices of Latin American partners, especially those directly engaged in the process (e.g. CBR workers), have rarely been heard internationally, including by those working in CBR in other regions. These voices and experiences are perhaps relegated to silence because of language, or because Latin America in practical terms continues to be (re)cast as a low development priority and area. The implication is that funds are lacking, and organisations go elsewhere. So does research. As I have commented elsewhere (see Grech, 2015), Latin America remains confined to the peripheries of imagination of those working in disability and development, as well as those theorising and framing toolkits and manuals. This also means that much of what we know about CBR, and that feeds into academic papers, edited books, reports and matrices, hardly reflects the Latin American context, experience and space.

So, when contemplating how to follow up the narrative workshop, the first issue was the absence of these Latin American voices and the need to listen and provide a platform for people to do so. As we refined our chats, and bounced back and forth with ideas, we reflected on what really made the narrative workshop a success. One of the factors here was the space for critical thought, and the articulation of critical perspectives in a safe space. People came ready to share their experiences, but above all, were adamant on questioning, challenging, debating and even arguing. This space and possibility, as it seems, remain scarce, internationally, but also in Latin America. In the 2013 CBR Congress in Colombia, a crowded space, I (Grech) was struck by how local organisation of the congress favoured a domination by non-disabled professionals and activists ('experts') presenting, with little if any participation by persons with disabilities, often talking down to them, and with no time or effort devoted to comments or debate (see also Weber, 2014). This led us to considering the second issue here: the need for a space for Latin American critical perspectives on CBR to question and reflect further in ways that not only tell a narrative, but that can usefully inform practice.

2.1 Objectives

This exercise, though very small scale, hopes to provide some insight into and feed into future critical evaluations of CBR and debates, a project capable of effectively listening to, learning from, and feeding back into practice as a continuous and iterative process. Time, funding and resources were limited, despite our intentions to pack in and learn as

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models (also as promoted in first CBR approaches in the 1980s) moving towards more rights based approaches in the early 2000s.

much as possible. This meant that we agreed that this was to be a small project, perhaps a first step towards a bigger project, but still one with ambitious aims:

a. To prioritise narratives and critical reflection as a source of evaluation capable of informing and activating potential change through learning rather than merely generating narratives for programme promotion and marketing.
b. Provide bottom-up reflective material which can also be shared (and possibly translated) with the rest of CBM management and field workers, opening other reflective spaces.
c. Enhance the knowledge base and learning of CBM around critical issues (including interpersonal ones) from region to region.

Using an online platform and focus groups/workshops with (largely) CBR workers and programme managers, the immediate objective was that of listening, prioritising perceptions and views and to articulate these voices. This opened up into a number of fluid objectives:

- To offer a safe space for participants involved directly in CBR to discuss and debate, reflect critically on key aspects of the notion/concept (CBR), process, practice and outcomes
- Learn about some of the needs of persons with disabilities and their families in relation to CBR programmes and other key areas through the voices of those working in the field
- Listen to participants' views about the program, including perceived contributions and successes, problems and gaps
- Provide a space to reflect on a number of professional, process, as well as personal and policy issues in their work, including staff development, adaptability and relevance of policy, guidelines and materials.
- Explore connections (or otherwise) between CBR and the CRPD
- Articulate the reflections of participants on other key issues e.g. overall design, implementation of activities, and participation
- Reflect on impacts on persons with disabilities, their families and communities.
- Explore measures (if any) taken to minimise exclusion
- Provide a space for participants to look forward towards the future and articulate some recommendations.

While this small research provided substantial qualitative information and narratives, it will become clear to the reader, that it raises more questions than it can answer. This is far from problematic, but is instead a welcome contribution of this open (and we hope participatory) exercise as it opens up issues and concerns for further reflection as well as research (formal and informal). As most participants clarified, CBR is a process, it is rarely complete, and so would we hope is the quest for learning and critical thought that is unconfined by boundaries.

3. Methodology

The methodology in this project is a blend of methods, reflecting our own need to adapt as we moved along. The approach is broadly qualitative in its focus on perceptions and voices especially of those seldom heard, providing an adequate exploration of themes, processes, descriptions, meanings and perspectives which cannot easily be measured or enumerated in a quantitative study (Denzin and Lincoln, 2000). It is also inspired by the principles and values of narrative research, especially in its emphasis that there is no defined beginning or end in research.

Like other small pieces of research, we needed to negotiate and compromise, especially on time, and the methodology transitioned over time. Originally, the intention was to set up an online platform (Google Groups) which would have served as a place for interaction, for sharing narratives, a place for critical debate. We did set up the group, invited quite a number of Latin American contacts, with the idea that the researcher (Grech) would have simply acted as a facilitator in an open and interactive online process. Unfortunately, registering took very long, and the process overall, it was clear was far from contextually relevant and adapted. Interactions were scarce, and despite the fact that quality, in-depth material and observations were shared, feedback was slow and too little. We discussed alternatives, and decided to use a blend of reflective focus groups/workshops in select locations in Latin America (El Salvador, Nicaragua and Guatemala) run by Grech to explore and discuss a number of key issues and explore these in-depth in a safe space. Focus groups (of approx. 15 participants each) were organised around the availability of participants and held in premises chosen by them. In all three cases, participants worked for an organisation identifying CBR as a key component of their work, or called their work CBR. Participants involved a blend of programme managers and field workers. The focus groups conducted in Spanish, included elements of a workshop, in that they also involved work within small groups to discuss, generate ideas, debate and write. This, we felt was a more inclusive and participatory approach, but also a means of stimulation and ownership of the process. The focus groups/workshops lasted a whole working day in an effort to minimise interference in daily work.

Compensating material generated online and these, was material drawn from other workshops and seminars using a fluid guideline, in Honduras, Peru as well as Nicaragua. Parts were generated by CBM colleagues, and others sent on via email from these locations.

Material from these workshops, together with data generated online form the critical data informing the analysis. The analytical process employed involved thematic analysis (Braun and Clarke, 2006), implemented with the objective of finding common emerging themes in the data, using a process of coding, that is the generation of categories and sub-categories. These key themes are presented below as key findings in respective sections and sub-sections.

3.1 Ethics

All ethical procedures were respected as much as was possible, given the limitations of online and group work, and the visibility and interactions they involve. The first communication on Google Groups mapped out some key ethical concerns. This included clear information about the project, rights of participants, and also the choice to anonymise the material they sent. Options such as those of sending narratives directly by email to the key research coordinator (Grech) were also offered. Those participating in the focus/groups workshops, were informed about the scope of the exercise as well as its output, articulated their rights, including that of withdrawing at any time during the workshops. Confidentiality and anonymity, as far is reasonably possible, were ensured when writing the report. To avoid singling out any individuals in the workshops, we decided to anonymise (as much as is possible) individual narratives.

3.2 Limitations and concerns

Like any other study, this small research project has quite a few limitations and caveats:

- This report does not claim to be the voice of Latin American CBR workers and neither does it claim generalizability to all Latin American CBR projects or even the contexts they are spoken about and from: this project is simply a small effort at listening and articulating the opinions, narratives and perceptions of a select group.
- It is not meant to provide a platform for inferences to other CBR projects, but simply to listen and learn from a small number of countries.
- Time and other limitations: travel and budget limitations meant working on a tight schedule, and not being able to extend contact with participants over time. This would have helped strengthen relationships, trust and the quality and extent of information shared.
- The coordinator (Grech) entered as an outsider, with very possible implications for feelings of suspicion, including whether this was part of an evaluative exercise on behalf of CBM, and whether this would have impacted the support they receive. This may well have conditioned responses and also experiences shared.
- Management and the presence of foreign advisors: Like any other research and work settings, one could assume that power relations are constantly operative, overtly and covertly, determining not only how interactions unfold, but also what people share and how they share it.
- Translation issues: much meaning is often lost in the translation, alongside the nuances of language, including localised words and expressions that do not exist in English or are not easily translated. We endeavoured to translate quotes in

ways that reflect some of the nuances and even idiosyncrasies of language and its use.

4. Key Findings

The following sections map out the key emerging themes. Where possible, we have included as many chunks of narrative as well as vignettes with stories and photos to support the analysis, and to open spaces for other interpretation. We also hope they can generate ideas and avenues for further research, reflection, and more importantly, practice.

4.1 CBR: unclear roots, unclear notion

This short qualitative exercise yielded substantial material about CBR, and indeed, workshops kick started with a short, but concise question: what is CBR? Participants were free to suggest a word or phrase they felt best described this notion or practice while also reflecting on the perceived origins of CBR.

While common strands did emerge, it was immediately evident that CBR was a rather confusing concept among most, not least in what they perceived its origins to be. Participants, as it seemed, had little knowledge of the formal history of CBR, the role of the WHO in the creation and promotion of this concept, and what led to discourse shifting away from institutionalised towards Community Based Rehabilitation. Participants in one focus group thought that CBR originated in contexts of war or as they called them, ‘developing countries’, while those in another, specified India or Africa, with no particular reason or evidence of this. When asked how they had shaped these opinions, some participants, especially field workers admitted that it was simply what they thought, had hardly read any background information, and had little knowledge of the roots of CBR.

While management were reasonably familiar with formal definitions of CBR, including the WHO definition and/or variations articulated by international organisations, field workers were not. The notion and practice of CBR, as it seems, has been absorbed, and then adjusted to the local context (see below). This reflects agency on the part of Southern partners, perhaps developing hybrid variations of CBR, adapted and localised.

It was interesting to note, though, that many participants felt that they were in fact doing CBR way before they got to know of the term, or before it was ‘brought in’ and introduced by external stakeholders such as CBM. As some articulated within the groups, it was simply a name or label that helped frame and conceptualise the practice they were already engaged in, something, they felt, was in practice borne on the ground:

> *I think that CBR emerges from the home, or from the needs of the person with a disability. In the home, or the surroundings of the person with a disability…We didn’t know, we had never received any CBR course, I simply remember X*

> *coming, leaving us a flyer with a brief summary of what CBR is, but we didn't know. What is CBR? It is about using common sense and using logic to say that this practice can be done in this way. This, too can be CBR, because this is how they trained us* (Group 1)

They did, though acknowledge and value the role of outsiders, in particular CBM, when it came to providing a range of support, including, as they expressed:

- A guide
- Help with shaping organisational structure, knowledge generation and (re)orientation of practice
- Filter: for ideas, tools, practice
- Source of material resources, in particular financial resources
- Suggestions on how to shape and improve practice
- Information on ethical processes in their work
- Source of novel 'foreign' ideas
- Source of culturally diverse ideas

The following quotes capture some of these observations:

> *For us, she (the CBR advisor) is a guide, because the fact that she comes to visit us and tells us: 'You should do this or that'. We take it on board, we take it seriously in the recommendations. And yes she helps us. And any doubt…yes we go to (her)…For example, X knows that if we are going to show some material and we are in doubt, if we made a mistake with something…but it is better to go through a filter. And for us, she was a filter, because on the basis of all her recommendations, we are now about to launch a load of material that will be used in the communities, in an exhibition we are having with the fieldworkers. Because any doubts, we do not hesitate to ask X and we know that she will help us* (Group 2)

> *CBM was a pillar for the organisation to develop as it is, that did not exist as an organisation before, that is through CBM we have achieved organisational strengthening, they have accompanied us from the technical-methodological evaluation through to this process* (Group 3)

The organisations reflected in turn on their respective roles in this relationship, with four emerging with particular prominence:

- Implementation of the projects
- Reporting (especially to CBM)
- Compilation of data
- Learning and teaching about CBR

While it is evident that the label 'CBR' has been embraced by these stakeholders, as well as those participating offline, an insider/outsider stakeholder relationship, though may still exist, and would deserve further research. CBR, it is important to emphasise seems very much recognised, including by persons with disabilities, families, DPOs, parents, other community organisations, and even friendly politicians on the ground. Still, it would be useful to question further the extent to which some aspects of CBR have been imported, and spread from the outside in, rather than in a bottom up fashion. This, though, may not necessarily be an issue of imposition. As one advisor commented, CBR may not have expanded so much 'from the ground up'; because it is seldom publicly discussed and because many projects remain small (too little funding and also visibility) and not because insider and local movements haven't been strong or determined enough. Nevertheless, and for the sake of asking questions, it would still be useful to enquire if and the extent to which outsiders' hold over funds, discourse, and the publishing of guidelines may impact a range of areas including priorities and directions in practice (see literature articulating similar concerns- Ingstad, 1990; Miles, 2007). This may perhaps reaffirm the need for critical insight into CBR, including outsider influence alongside localised concerns such as the lack or absence of willingness of some governments to take over and manage (also in conjunction with organisations) CBR programmes[2].

It was interesting to observe that while most seemed comfortable with the name CBR, participants in one focus group in particular, expressed how they felt uncomfortable with the word 'rehabilitation', highlighting in turn a preference for Community Development (*Desarrollo Comunitario*). Participants in another group offered other alternatives including: '*Desarrollo inclusivo comunitario'* (Inclusive Community Development)*, 'Desarrollo Inclusivo con base en la Comunidad'* (Community Based Inclusive Development) and '*Inclusividad desde la Comunidad*' (Inclusion from the Community). This reflects broader shifts in other spaces (including in Asia) and programmes towards other terms including Community Based Inclusive Development. This terminology is increasingly supported by institutions such as the WHO and the Pan American Health Organisation (PAHO) (see www.paho.org). Indeed, even the WHO's disability and rehabilitation unit (DAR) has initiated efforts at renaming CBR, *Community Based Inclusion* (CBI). Many of the participants stressed how the word 'rehabilitation' medicalised, denied potential and capabilities, placing the focus instead on 'lack', on people who are 'sick', and who need to be normalised and treated:

> *Medical knowledge has always had alot of power in the field of disability, and today…the word 'rehabilitation' means getting the person to reach a state of normality that comes from.. that the medical perspective conceptualises 'normal' as a condition of health we all should have as individuals* (Group 1)
>
> *What I hear alot of, is that rehabilitation is for someone who is ill, that is what I hear, I hear that rehabilitation is to say 'he is ill and one has to cure him/her'* (Group 1)

Discussions within the groups also highlighted how professionals, including medical and academic ones, sometimes capitalise on this situation, repositioned as 'the experts' on disability, while ignoring or devaluing the invaluable work done by CBR organisations on a daily basis. Participants in one group expressed deeper concerns, including how

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[2] There are, though, some governments e.g. Nicaragua, Bolivia, and Ecuador currently looking into a strategy to take over CBR programs (and even accompany CBM in doing this).

CBR was perceived by others, especially professionals and politicians as lacking quality or of bad quality, a replacement for 'proper' treatment and rehabilitation. They also articulated another critical issue: that CBR may be perceived as a project that does not require resources. The result is that some local politicians may not too easily provide the support (financial or otherwise), including linkages with those who can. Even more critically, while support is needed and is a first step, governments need to take responsibility and then take the lead. This level of support is even harder to come by. I will pick up these issues more in-depth in a later section as we discuss problematic aspects. But it is important to note that decentralised support (municipal level) is not always absent, and when it does exist, may come with reasonable levels of commitment to CBR. While the financial support may not be enough to fully fund CBR programmes, it has potential to somehow contribute to the sustainability of CBR and reinforcing it as a credible and viable option. The linkages between municipal support, CBR and sustainability are an area that requires in-depth study.

4.2 Conceptualising CBR

In the absence of knowledge of an all-encompassing definition, including that pushed forward by the WHO, manuals and other formal documents, participants articulated their own notions of CBR. They offered multiple words they felt described CBR as a concept, process and outcome. Some of these are presented verbatim in the table below, highlighting a wide and also heterogeneous range of understandings, though not without common points of encounter:

- Service
- Potential
- Strategy
- Tool
- Guidance
- Help
- Resources
- Work
- Participation
- Education
- Alliances
- Love
- Team
- Guide
- Empathy
- Inclusion
- Quality of life
- Management
- Confusion
- Necessity
- (Self)learning

- Community work
- Inclusion (of persons with disabilities, children, family, community)
- Diversity
- Change
- Opportunity
- Empowerment
- Willingness (family, political, religious etc.)
- Socialisation
- Rights
- Solidarity
- Humanity
- Accompaniment
- Commitment
- Inclusive Development
- A process
- Integration
- Integral
- Community
- Unity

Participants in the workshops were invited to reflect on these key words, and to work in subgroups to come up with their own definitions of CBR. This was an interesting process, not least because none of the focus groups made reference to the formal definition employed by international organisations, formulating instead very creative and empowered definitions. I reproduce a number of these in their entirety:

> ***A flexible tool*** *that allows communities to offer and generate opportunities for* ***comprehensive development...****from the* ***promotion and protection of human rights*** *and to* ***inclusive development*** (Group 1)
>
> *It is a* ***participatory strategy*** *of* ***help*** *to persons with disabilities through resources and tools for support so that they reach a better* ***quality of life****, by asserting their* ***rights and opportunities*** *through* ***inclusion*** *and* ***integral care****, developing their potential, permitting them to improve, become* ***independent*** *and be* ***productive persons*** *in their community and social and family environment* (Group 2)
>
> *It is a strategy that offers* ***tools and guidelines*** *to include persons with disabilities in society and create development through the resources of the community and* ***inter-institutional management*** *to reach the* ***achievement of rights****, generating* ***commitment by everyone*** *(family, communities, governments, NGOs)* (Group 2)
>
> *It is a strategy that…requires* ***changes in attitude*** *in communities,* ***will power*** *to make reality the achievement of the rights of persons with disabilities* (Group 3)
>
> *It is a programme that attends to children in for example,* ***rehabilitation*** *in accepting the reality of the disability they have. To* ***include them in all sectors, education, work,*** *everything…* (Workshop, Peru)
>
> *It is a* ***multi-sectoral*** *strategy that helps through its actions. To* ***inform, socialise, social communication****, rehabilitation, inclusion,* ***empowerment*** *on rights of persons with disabilities and develop capabilities… autonomy in access to health, education of persons with disabilities* (Workshop, Peru)

4.2.1 CBR: from heterogeneity to common strands

Looking at the descriptions and definitions offered above, it is clear that CBR is not a clear concept or notion, and much less, a clear method or output. Importantly, there is no agreed definition among those working in it, but to be clear, neither was it planned to be a structured or definite concept. This is far from problematic, and perhaps a strong point of CBR, making it, as it seems a malleable concept and practice in Latin American contexts that are used to adapting, and that are importantly, constantly changing- contexts that are packed with agency (Grech, 2015). Disability, conditions and circumstances are constantly changing, and persons with disabilities, families and communities are heterogeneous (see Garland- Thomson, 2005). The range of words used above, in particular the focus on process, adaptation and change, point to the need to look at CBR as not only fluid, but also a concept that needs to be continuously (re)defined.

Reflecting broadly and outwards, participants in the three focus groups went on to debate the notion and practice of CBR. While understandings were varied, and there didn't seem to be one definition endorsed and applied, it was clear, including among those participating offline, that common strands and understandings of what CBR might be, its objectives, and how it may go about achieving these, do exist. This is evident in the definitions offered above. I attempt to capture some of these in main the points below:

a. <u>CBR is a process</u>*:* it has no definite beginning or end, it is continuous, adaptive, and dynamic:

> *Step by step starting from self-assessment to programme development and implementation* (Group 3)

As a process, though, it may not always be smooth, move in positive ways or have positive impacts, but is instead iterative, dynamic and sometimes turbulent. An online participant captures this idea succinctly:

> *For me, it is a dynamic and continuous process that goes through various stages depending on the social dynamic and the specific context where it is applied. As with all evolutionary processes, it can also regress, and start again, sketching a unique spiral across time* (Group 2)

b. <u>CBR is a strategy</u>*:* in working towards the rights and empowerment of persons with disabilities, but also their families and communities. Again, as a strategy, it is simply a tool kit to be used by those working in the field:

> *It is a multi-sectoral strategy with a focus on rights to reduce poverty, discrimination, general opportunities for integral development…equal conditions as everyone else* (Workshop, Peru)

c. <u>It is a means and end in itself</u>*:* as a means, CBR is the strategy and toolkit contributing to well-being, but its boundedness to rights and community development for the well-being of persons with disabilities, makes it an objective to aspire to:

> *… on one hand it is a strategy for the well-being of persons with disabilities and their families…and on the other, it is the hope, that persons with disabilities are happy, and that their rights are entirely respected* (Online)

d. <u>CBR is about change</u>*:* in structures, the social and physical environment, policies, attitudes, services, but also personal change and empowerment, for example in well-being (including psychological aspects). It is about providing access to health, education, and a better quality of life overall. CBR, as most participants emphasised, is critically about inclusion, one that is holistic (see point below), and which involves educating community and society.

e. Rehabilitation is about change, and this change is multidimensional and comprehensive*:* it transcends health to cover personal, social, economic, cultural, policy, service, religious/spiritual, ideological and attitudinal and other dimensions:

> *Working with CBR and seeing the person as a whole, not only the aspect of health, and yes there is poverty, and yes one has to pull him/her out of this cycle, and there yes there is integration and to include him/her in all areas* (Group 2)
>
> *Generate opportunities, work opportunities, to have development, rights, changes, including emotional ones, for example, changes in self-esteem…one can also take into consideration changes in the social environments, this change refers to the fact that even society considers worthy the contribution that persons with disabilities make to the community* (Group 3)
>
> *Each person, health, rehabilitation, education, livelihood…all must have a comprehensive vision and must work together. It is a change in attitude. What happens in our society is that this comprehensiveness is what is lacking. We need to change this mentality, as health personnel, I must connect myself with education. The community needs to learn a more comprehensive way. Being human is comprehensive, not segmented* (Workshop, Peru)

f. CBR is cross-sectoral*:* it involves dialogue and implementation across sectors, including, among others, livelihoods, health, education, infrastructure, justice, and communications.

g. It involves promoting, working towards and educating about rights (of persons with disabilities, their families and communities), so that people can claim them:

> *What interests us is not that people know of the project, but that people know about rights. If people or the person knows about rights, everything else is a plus. If he/she knows that health is a right, then he/she will know that in the community there must be health care. Equally, if education is a right, to know that in the communities there is inclusive education* (Group 2)

h. *CBR* is concerned with 'development', more specifically 'inclusive development'*:* while the latter remains an elusive concept, participants in workshops articulated ideas about what this might mean: change; personal and social change; better quality of life; independence; participation; productivity; empowerment; accessibility. One group defined 'inclusive development' as 'Inclusion starting from the community'.

i. Well-being and empowerment are targeted not only at persons with disabilities: but also families and community. Still, improvement in the quality of life of the person with disabilities must remain firmly in focus and the priority.

j. <u>Family and community are critical</u>*:* participation is fundamental in supporting the person with disabilities, accessing services, impacting his/her well-being, and giving continuity to CBR as a process. Families provide much psychological and material support, but as CBR workers stressed, can also be a source of barriers, for example through over protection. They therefore need to be roped in as genuine partners, while CBR workers must focus on changing attitudes and providing support mechanisms including gatekeeping, linkages to key services etc.:

> *Without family and community, this is impossible…because they determine how CBR develops, and how they support the person with a disability…and also because there are attitudes there that affect the person, and that is where we (CBR workers) come in, like a bridge*… (Online)
>
> *In the Andean world, it is about living well, you live well with your surroundings, and your community contributes too. It means 'forming part of'. The first environment is the family, they (family members) have to include the person. Respect too is important, and this is 'good living'…Family is the primary environment. The family have to take the person with a disability into consideration, including his/her opinions and rights. And then, as a second social surrounding, comes the community… to build the community together with the person. With this strategy, the subject of including the person with a disability in society and respecting his/her rights, has been developing* (Workshop, Peru)
>
> *Rehabilitation is directly with the person with a disability, but included too, is his/her environment. For the person to be able to rehabilitate, we have to depend on the family and the community, for acceptance and empowerment of the person, so that changes can happen* (Group 3)

It is clear though that involving family and community means that these are not simply roped in, but must be transformed in the process:

> *The community has to transform itself for the achievement of rights…the core that interests us is to carry the person with a disability towards entitlement and rehabilitation, and we have to drive these changes and transformations in the community to be able to achieve rights* (Group 2)

k. <u>CBR emerges from and is moulded around communities, their experiences, their engagement with disability:</u>

> *The experience, really, CBR emerges from the same communities, from the good experiences of people… the bad ones and the good ones* (Group 1)

l. <u>It involves creating awareness among policy makers, service providers, communities and others</u>*:* so they can support and contribute to inclusion

> *We have tried to create awareness among organisations, municipalities, so the state assumes it as a responsibility. Community is a space to live together to reach a harmony. This harmony is a constant struggle we aspire towards. Inclusion has to form part of this democratic space, so they too can contribute* (Group 1)

m. <u>It is flexible and depends on flexibility and responsiveness to change</u>*:* CBR depends on being able to shift and change as circumstances vary, and this flexibility is needed not only by CBR workers, but also by persons with disabilities, their families, community, policy makers, service providers and others.

n. <u>A process of learning and (self)change</u>: by persons with disabilities, families and also those working in CBR, and hence involves change in approaches and programmes too:

> *CBR has evolved alot from the time we started off with the traditional model, and we have learnt many lessons, now we understand how the fieldworkers, the ones who survived emigration have served as examples for their communities, and we have two who have already made radical changes in the area of accessibility* (Online, Mexico)

o. <u>Looking for and forming alliances and collaborations is key</u>*:* this involves community as well as other organisations (especially Disabled People's Organisations (DPOs), political leaders and municipal authorities, national policy makers, universities, churches and others. While time did not afford such an in-depth exploration of these alliances and collaborations, it was evident that CBR and CBR organisations do not function in isolation, and are indeed dependent on relationships they shape, and the functions and roles they share with others. This includes tapping into services offered by other organisations (national and international) (e.g. in health, assistive devices, and education), and building bridges with other service providers and those lobbying and working in other fields, including gender and childhood. These may contribute not only funding, but also exchange of knowledge and learning. To reiterate, these collaborations require more in-depth research:

> *On some occasions, and only on some occasions, we coordinate with the municipalities, which are the local governments, for example, we manage together the transport to mobilise people…for some evaluations that are conducted, so there is coordination with certain government entities, local governments…the registry is also a national entity with which we collaborate* (Group 2)
>
> *And so now, already working with CBR, the same person comes to an appointment, identifies him/herself, but apart from giving him/her the medical care he/she needs, he/she also receives more specialised care. And that is where alliances with other institutions come in* (Group 2)

p. It involves empathy and understanding and is sensitive to diversity

q. CBR is not cheap, and cost-cutting may impact quality and sustainability (see below for more on costs)

> *Working cheaply means cheap work* (Online)

r. CBR may be erratic and difficult to plan*:* as a dynamic process, it is dependent on and conditioned by various extraneous factors (including funding, political support, participation of families etc.), it is often difficult to plan ahead and requires adaptive tweaking at various points. As one participant put it, CBR 'is not a structured programme'.

s. Not charity: most of those in focus groups stressed that CBR is rights-driven, emphasising they did not promote handouts. Consequently, they highlighted how they asked for a contribution for services[3], however small, framing it as a 'symbolic contribution':

> *…despite the fact that we had the opportunity to give everything for free: consultations, vitamins, medication, we (the organisation) never gave everything for free. Because we were seeing that people would give more value to things when having to pay something symbolic than having everything handed out to them. Because people would think: 'if they give me everything for free, then it is not good'. And so it is better if it costs them even something small so that they value it. So none of the programmes have been entirely subsidised, hundred per cent.* (Group 2)

The perceived common strands mapped out above, were indeed confirmed by what participants in two of the groups saw as practices, including behaviours and attitudes, which are not or can't be called CBR. The words and phrases used to describe these, included:

- Decisions without the person
- False expectations
- Indifference
- Working in an isolated way
- Excluding other organisations (e.g. municipalities, churches etc.), families and communities
- Discrimination
- Exclusion
- Imposition
- Working cheaply
- Ignorance

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[3] It is important to note that this is not accepted everywhere. Indeed, one advisor reported how in Nicaragua the government has prohibited financial contributions.

- A structured programme
- Charity
- A recipe
- Lack of willingness
- Something initiated from the outside.
- Something static

4.2.2 CBR, rights, policy and the CRPD: linkages

The mentioning of rights was frequent, with participants, offline and online, stressing that CBR not only has a role in contributing to the achievement of the rights of persons with disabilities. Importantly, CBR and rights exist in a tight symbiotic relationship:

> *Rights are what stimulate CBR in the first place, so that persons with disabilities can have a good quality of life and live equally as anyone else, and CBR stimulates rights* (Group 1)

As this quote suggests, rights are an objective to be reached through their work in CBR, but also an end. CBR workers are instrumental in this process as guardians and promoters of rights achievement and promotion:

> *Without doubt, despite the difficulties, we believe that this strategy (CBR) is contributing to the achievement of the rights of persons with disabilities, because we have become the companions of persons with disabilities and their families in the protection of their rights* (Workshop, Honduras)

> *We work with the hope that persons with disabilities can have rights, to work, to get an education, to send their children to school, to live satisfied just like any other person* (Group 3)

Policy was mentioned frequently, in particular national disability policy and the support it provides in framing but also supporting CBR work as a holistic strategy, and holding institutions to account. These explanations by Peruvian partners online, sum up a number of aspects:

> *…yes, very important because it helps us to demand they fulfil their responsibilities…of great use, maybe without this law, we would have only thought of health campaigns. With this law we have organised awareness campaigns, for teachers, DPOs...it is an advanced law that includes all the rights, it has pushed aside the charity focus, the medical one of disability. It has opened the door for us to work on through a participatory paradigm. On the subject of education, we work on it as it is in the law. It has backed our proposals* (Workshop, Peru)

> *It is important that the law textually mentions CBR as a strategy. This legitimises our experience. It is not only for the rural zone, but is instead a different way of thinking. The law has allowed us to visualise the CBR strategy. It has backed us*

> *up. In the area of accessibility, they speak about universal design. It opens a range of possibilities: not only physical accessibility, but also in communications, technology, above all changes in attitude. Then the subject of empowerment: persons with disabilities are recognised before the law. They have their own life in society, same with DPOs. It is important because it legitimises the work of DPOs. All this approach of working with a social focus, of rights, of the law, allows us… to conceptualise disability, and this is in line with the UNCRPD. I believe textual. Now it allows us to use certain terminology. For example how to name the person. No longer 'exceptional persons' or 'special', but 'persons with disabilities', not only because the law says it, but it is a new perspective. Another contribution of the law is that it speaks about childhood with disabilities. Now it talks about comprehensive development, the protection of children with a disability* (Workshop, Peru)

The CRPD was reasonably mentioned in the focus groups, and it was clear that this provided impetus to work harder, strengthened ideology, and there was quite some hope that it constituted an overriding political tool that pushed for and challenged national policy when it did not deliver:

> *It is important because the countries that are signatories have had to make modifications to the laws of the country in order to adapt and fulfil it. Here in the country right now there is a movement of DPOs, not only here, but in all the country, that is in discussions because there is a certain vacuum in the equality act, and the equal treatment act is under the umbrella of the Convention, and so what they want to do is that there are no longer these vacuums within the law of equalization of opportunities because this leaves a space for it not to be fulfilled, and because of this there is space to evade responsibility so to speak, both by society as in the case of employers for example when it is a person in search of work. And so, yes the Convention is important, because it is an instrument, like it or not, that the State has signed and also has an optional protocol, and so it obliges the State to fulfil it, to ensure the fulfilment of the rights. And thus there is compliance not only in the law in force in the country, but also in the rights established in the Convention* (Group 2)

It also, and more basically, opened a channel for communicating with politicians:

> *So first there is the need to convince them (municipalities), the committee members. And then to talk to them (persons with disabilities) about the Convention so that they feel empowered and have the power to reach the Mayor's office and say: "No, but look, it is the government that has to ensure the implementation of these rights"... If we had not spoken of the Convention or of the rights of persons with disabilities to the members of the committee, I believe it would have been quite difficult to convince them* (Group 2)

For many, it served more than anything, to reinforce the discourse against charity, and that the fight was one for rights and equality. It supported the concerted effort at challenging what participants frequently called 'paternalism' (*paternalismo)* and 'handouts' (*asistencialismo)*, including symbolic paternalism.

It was interesting to note that when challenged further about the notion that charity may be operative even within communities, and not necessarily in harmful ways, participants in two of the groups stated that it was handouts they had a problem with, especially ones motivated by 'pity'. These encouraged dependence, and ultimately compromised the quest for rights:

> *To help people is okay, but it doesn't stop here, just giving money or any other thing isn't the solution, at least, not forever, so one has to educate people about rights and that they have to fight and never stop* (Group 1)
>
> *What happens is that very often we confuse the term 'charity' with 'pity'* (Group 2)

Unfortunately, this approach faces an uphill struggle when confronted by diffuse charity images in Latin America, such as those promoted in the Teletón[4], consistently pushing rights further back into the policy and service background:

> *…it fosters pity to see a person who is chained, or dirty, with no food, with no clothes. And so the person says: 'Poor person, I'm going to give him/her a hand, I'll give money for this person'. But it is seen from another perspective, charity based on pity. One doesn't do charity if this person has rights* (Grupo 2)

All groups, to some or other extent, emphasised how CBR provided and supported a language of rights in contexts where there was too often no committed public policy, and much less, enforcement. It was therefore part of the CBR strategy to achieve parts of the CRPD. Nevertheless, adaptation and using what 'worked' in this context appeared key:

> *And so we believed that there were only ten rights. And when we saw the number, it was a shock to us, when we received this course online, because they spoke to us of the rights commission. And reading it, which was a task they asked of us, we read the rights and that they were fifty, and of the fifty we chose the ten most important for us. And then we drew out some comparisons* (Group 2)

It was, though, possible over the course of debates (online and offline) to see that in practice the linkages between CBR and the CRPD appeared loose and fluid, backed by scarce knowledge of the actual content of the CRPD. Indeed, while most of those in the workshops mentioned rights and the CRPD as an effective political instrument, whether in lobbying governments or a benchmark against which to work, it became increasingly evident that few, especially the field workers, had actually read any of its content. But let's face it, one would imagine, not many have read it from page to page. There was also little knowledge about the journey of rights (origins, language, discourse and

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[4] The Teleton is a charity event present in many Latin American countries, the objective of which is charitable fundraising for disability, with the idea that the funds are then dispensed to a number of organisations. Criticisms of the Teleton are many, especially among those working in the disability and rights sector (including in CBR), mainly that it depends on and reinforces charity and charitable images of persons with disabilities. Others (see Grech, 2015) also document corruption in the selection of beneficiaries and dispensing of funds.

political developments), including in Latin America. This does not necessarily dilute its relevance. In fact, a number of focus group managers stated how they would mention the CRPD with local politicians when they witnessed injustices. In this role, they also tried to informally educate about the existence of the CRPD. These claimed that the CRPD also constituted a strong tool to put pressure to modify existing national policy, to make demands as best as they could, even though, as most admitted, these demands were rarely accommodated in practice. Indeed, indifferent politics and politicians, lack of knowledge and information about rights, and the reality of poverty, were strong factors and barriers, diluting the power of the CRPD as it met very real and concrete obstacles (see also Soldatic and Grech, 2014; Grech, 2015 for more on these barriers):

> *Are we fulfilling the law or not? It is not only about the law being written, but that it is fulfilled. And who is going to guarantee that it is fulfilled? It should be the State. The State is not executing the functions it should... we are far from achieving compliance...And so when we started talking, we used to say: it is important for us to know it, but it is important that we demand compliance* (Group 2)
>
> *I believe that CBR knows the Convention. The Convention does not know CBR, and so it is difficult…Conventions are global frames, so adapting them to reality is very difficult* (Group 1)

Barriers are not only political, but also include those of limited resources and over-stretched organisations constantly multi-tasking:

> *The problem is that it gets complicated because we are, like, specialists in everything, and at the same time, specialists in nothing* (Group 1)

Participants in this same group reflected further on the interactions between CBR and the CRPD, highlighting how the CRPD was ultimately more attractive in financial terms, meaning that at least in discursive terms, people were more prone to latch on to it than CBR. This included random politicians and organisations working in other sectors. Within the disability sector too, not all voices and countries are as powerful or equally represented, and some do feel left out:

> *CBR, I believe, does not generate money. But the Convention, I believe, yes does generate money. And so when you have something that generates money, then even governments rapidly grab it and apply it. That's what I think… The truth is that all the laws, for example the disability law, comes from a source. And you know what the source is?...The Convention is the result of people who gather to talk about human rights... delegates of... And I don't know how much influence a small country like ours has in a global forum. It is as if we were speaking about the United Nations Security Council, that (the country) was part of, and how much did the country influence in that space? I imagine that it is somewhat similar in those forums* (Group 1).

4.2.3 Guidelines and matrices: do we need them?

As discussions developed, participants also reflected on the role of the guidelines. All three focus groups saw some or other merit in CBR work. One group commented on how the guidelines were useful in orienting their work, taking the ideas into the community, and how the matrix was handy when it came to checking and ensuring they were covering all priority areas. The group also commented that these were not carved in stone, and how while not everything was relevant to the context and contexts they worked in, there was space to adapt them, which was a key perceived strong point:

> *When we read the guide and that a person with a disability has the right to get married, and we started talking about involvement in cultural aspects. So we tried to bring it to the communities too. Yes we have read the guide, and yes we brought it to the promoters and fieldworkers. And yes, there are things that are feasible for us, and others that are not* (Group 2)

Another group also noted how the guidelines were accessible and a helpful way in implementing the CRPD. Participants within this group, highlighted how in practice they had only (at best) read parts of the guidelines, but which they felt were flexible enough, and provided the opportunity to link with and build upon their already existing knowledge base:

> *We all have them, but reading them directly, something aside, not all, but yes we have used some of them, including where there is the summary... I consider that it is necessary. But in practice we combine this with knowledge... the information that is in the guide gives us an idea to shape more programs, to work with persons with disabilities* (Group 3)

Contributions from other spaces, online and offline built up and extended from these perceived merits highlighting other attributes including: the generation of ideas, conceptual developments, and fluid programme guidance:

> *…to have more ideas on ideas to have to support families* (Workshop, Peru)
>
> *…in truth, they have helped me more as a theoretical support* (Workshop, Peru)
>
> *It has been like a process. Because the team was small, the team of field workers together with the promoters, facilitators. And that team was building up, and each month we proposed a theme, a theme that was consistent with what was CBR was, but expanded. They gave us the guidelines, we started to get from them all the basics. We could not do everything that was in the guidelines, we cannot work... the matrix for example. But someone got the issues of health, education, worked a bit with empowerment, and socio-economic inclusion* (Group 2)

The quote above usefully suggests a contribution of the guidelines, in particular in broadening the areas of intervention beyond health and rehabilitation, driving attention towards the various areas and intersectionalities. In line with this, one group insisted how the guidelines contributed to a paradigmatic change or rather the notion that ‘rehabilitation’ is a broad and multidimensional notion:

> *I also feel that the CBR guidelines help with paradigmatic changes. It is a foundation of CBR that shows how in a rehabilitative medical model, a person with a disability only needs therapy and mainly occupational therapy. But, in the CBR guidelines we can see the different components and how community levels are needed to strengthen what is already being done* (Group 3)

Nevertheless, one group in particular was consistently more questioning and critical, insisting that these guidelines were ultimately something they had already figured out on the ground informally, and didn’t necessarily need them. In practice, they were, as they suggested ‘little more than common sense’. They were simply a ‘label’ without which they would have still functioned effectively:

> *We were already working without the guidelines, without knowing the guidelines. We realised that the person not only had needs in education, health, but we were looking at the issue of work and all that. When we look at the guidelines, the only thing that they show us is that yes there is the need to work in a comprehensive manner for the person. But the guidelines do not necessarily come to give us all the solutions, and so it should be, because we were already working that way, or rather, we were already doing it, without reading, without knowing the guidelines... We were born using common sense and logic of how things should be done. If you ask whether I have read all the guidelines, no I have not read all of them* (Group 1).

When engaged in more critical debate, though, all three groups expressed how despite their flexible contribution, there were still aspects that were lacking or not emphasised enough in these guidelines to make them completely useable, and at times, relevant. For many, the use of these guidelines was often erratic on account of some perceived limitations in these. These included:

- Weak linkages with policy and government: the guidelines, participants commented, seem insufficiently alert and sensitive to the power of policy, government, and other stakeholders in determining the trajectory, modality and success of CBR in practice. Reflecting on micro-politics and their impact, one person in one specific group commented that the guidelines and CBR more broadly may even remove responsibility from the government, making disability the responsibility of CBR workers and small organisations alone. It is important to note, though, that anecdotal/secondary information suggests that in some contexts, this may not always be the case or only to a certain extent. For example in Nicaragua, training on the guidelines has been extensive, with government supporting on this training and opening it up to a country level (all departments), including those working in health, education, and livelihoods among others.

- Legal body: in line with the above, participants commented that the guidelines were useful in guiding their work, but had few linkages with disability and other policy and had little direct influence over these.
- The reality of lack of opportunities and limited influence confronting persons with disabilities and families:

> *When it comes to work, employment, we do not have like a fund for work… I know that people in the community have (a qualification), have studied even up to a certificate level... University level we practically do not have... If there is a job opportunity we communicate with the person and establish the contact. But we do not manage this, we do not get involved directly in approaching institutions: 'look, I have so many persons with disabilities that you could (employ)'* (Group 2)

- Little focus on adolescence
- Scarce alertness to the prevention of violence of women and children: this is a very serious concern considering global evidence of higher levels of vulnerability to violence among disabled populations (see Chouinard, 2012):

> *As well, one thing that perhaps is lacking is prevention of violence. We are speaking about a person with a disability, who for having a disability, for being a women, faces double the risk of violence. And so how to include this theme too* (Group 2)

- Knowledge of these guidelines by university lecturers and other educators is lacking if not inexistent: this compromises the formation of alliances and diminishes perceived relevance of their work.
- They are costly to implement in practice: participants were emphatic at various times that following the guidelines required resources they often did not have in sufficient amounts and regularity.
- Personal experiences are missing from these guidelines
- Contextualised experiences are lacking: one group in particular reflected how they felt the material informing these guidelines may not have been completely relevant to their own contexts or based on these spaces and concerns.
- Knowledge of the experiences of other organisations: one focus group alerted to how the guidelines provide a sort of template, but are not backed by, and do not emphasise exchanges between organisations. These, they suggested could provide a space for the exchange of knowledge, success stories, sharing of information on implementation, and importantly help avoid repeating the same mistakes.
- Audio-visual methods to account for illiteracy: the same group insisted that the guidelines would have wider usability in audio-visual format for literacy, but also

> for cultural reasons, and which would help them be more personally, culturally and contextually adapted.

Participants in other workshops, summed up some of these issues, highlighting perhaps how the guidelines are also more of use among middle and top management for strategy rather than CBR workers in the field:

> *Many examples are very distant from our context. You don't feel they are yours. But the theoretical support, yes. You have a didactic management of themes. I liked the part about disasters, but in truth we have not worked in it….we use parts of the guidelines in our presentations. In fact it is a resource. The guidelines are a basis upon which to suggest regional strategies* (Workshop, Peru).

Finally, one group, in a brief reflection on the CBR matrix, suggested how this may not be adequately sensitive to the heterogeneity of disability. Nevertheless, they insisted they were aware that the matrix was not there to be followed with precision:

> *I don't believe that it is its role, because what the matrix is based on, logically so, is the necessity for comprehensive care for people. But we are not looking enough at the issue of heterogeneity, the individual and all of this* (Group 1)

4.3 Reflecting on 'impact'

Impact has become a buzzword in sectors such as development as well as disability-inclusive development. Many are trying hard to prove their work is having impact, whether for funding or for marketing purposes, and much effort is dedicated to trying to prove something that few can in fact define or are in agreement about (see Chambers, 2012). Everyone everywhere seems to be chasing the spectre of impact, but no one really knows what we are talking about.

While participants online and offline, were clear in suggesting they felt their work was having an impact on persons with disabilities, families and communities, responses to what they actually understood by 'impact', or when they knew their work was having an impact, suggested that in practice, much lack of clarity surrounds this term. This did not mean that they didn't reflect on what it could mean. On the contrary, participants in groups offered multiple understandings, suggesting a pluralism of understandings. Impact is packed with subjectivity, and tick-box approaches (such as those in structured monitoring and evaluation exercises) are unlikely to work because many dimensions can hardly be enumerated or captured, including 'well-being'. While participants were clear in stating that impact was important to them (for drive and motivation), that it served the objectives of funders, and that they were required (directly or indirectly) to show that their work was positively affecting people, they were still unsure as to what this meant. The breadth of ideas expressed around this notion, do though, highlight some common perspectives, in particular alignment with more popular quantified or quantifiable objectives- that it is about something anticipated and/or outcomes that can be measured. Nevertheless, it is more than evident how these are offset by more fluid, holistic, subjective understandings of a notion that is changing, multidimensional, and hard to control and perhaps even anticipate. The range of reflections and descriptions of 'impact' from the three focus groups are presented verbatim below:

- Something that can be **measured**
- **Success**
- **Support**
- Both **quantitative and qualitative**
- Results obtained **in line with defined objectives**
- **Tangible**
- **Commitment**
- **Transversal**
- **Sustainable**
- **Quantity** e.g. number of persons supported
- **Good** or **bad outcome** that is **not expected**
- Something **long term**
- Various **changes:** vision, dreams of the future etc.
- **Participation** and Involvement
- More **freedom**
- Something **new**
- Something that **leaves a mark**
- **Independence**
- **Less poverty and suffering**
- **Rights**
- A **model** to follow of good practice
- **Empowerment** of persons with disabilities (spirit, enthusiasm), families and communities
- To generate **opportunities** for persons with disabilities and their families
- **Inclusion**: a diverse community
- Change in **attitudes**: the person with disabilities accepts him/herself
- Acknowledging and attending to the **needs of each individual person**
- Attention to the **heterogeneity** of disability
- **Flexibility**
- It **emerges from the ground** (not from the outside) and the community, and involves community participation.
- **Independence** and self-management, including deciding autonomously how to spend money
- Take **decisions** in a self-determined way
- **Personal development**: that is physical and intellectual, and this is a process
- Laughter and **happiness**

It is possible to reflect further on these, and in particular to mark out common themes. For ease of reading, I have highlighted these in bold. In particular, it is clear to see how impact has both qualitative and quantitative dimensions, and how much of it is about personal and familial development. It is also about a leaving a mark, a legacy, and this impact is multidimensional. This has serious implications for how it is understood, but also for how it is 'documented' or 'measured'.

4.3.1 CBR: perceived contributions to discourse and practice

Participants reflected further on impact and in particular on CBR and its perceived contributions. As the conceptualisations in the early part of this report suggest, views about CBR were very positive among those working in it. Participants online and offline expressed how CBR gave hope to families with little or no support, and despite the fact that many claimed to already have been performing this work informally, CBR made them feel part of something bigger, an idea, perhaps a movement:

> *It is a movement, a collective struggle for the well-being of persons with disabilities* (Group 2)
>
> *CBR gives hope to families who would not have any support without the programme, we work in many areas and we give hope to persons with disabilities through our work* (Group 3)

Those working within groups, as well as those online, shared a number of stories, including personal ones, suggesting a CBR process that is needed, called for, that has impact, and that may indeed be a one-stop shop for anything disability, especially in poor communities. The following is a synthesis of the key positive aspects perceived:

- CBR has in some contexts helped reframe and perhaps shift cultural and religious/spiritual beliefs about disabilities and their origins. The following excerpt highlights how the notions of 'disability' and 'rehabilitation' were reframed through CBR, how this challenged and repositioned traditional ideas, including beliefs that disability was a result of sin:

  > *…I still don't know where CBR emerges from, that is, every social context gives it a name, but…from the religious point of view, it (disability) was a subject of sin, if a person was born with a disability, it was because he/she was carrying some sin….if one sneezed in the morning, it was like a bad omen, this is why they would say 'bless you', and if you sneezed in the afternoon, it was a good omen. And so the subject of CBR too has its context….in religious terms, if a child was born with a disability, it was a 'sin', but then came another transformation of ideas and there we move on towards the context of rehabilitation…But after this, we get to the theme of the social, of social inclusion, and so this journey has developed along with the subject of disability and emerging strategies* (Group 3)

- CBR is contributing to facilitating access to services and life spheres, such as health and rehabilitation and education and work, especially for those with few means to do so, and may (directly or indirectly) be contributing to positive change including poverty reduction and inclusion:

> *People already know their rights, and people and their communities speak about rights, people from communities are no longer set apart, that is, hidden in the house without the family knowing. Persons with disabilities too are working. Before, they didn't have the means …They didn't go out to look for work out of fear they would be rejected* (Group 2)

The following lengthy but detailed narrative, documents the journey to get a child into a school, one of building bridges and changing attitudes:

> *...we have a school where there is a child with Down's syndrome, and he does not go to school every day. And the teacher came to one of these training sessions and she took him back, because we used an example of a child we met in X (location), a child with Down's syndrome, who was very restless, he hit the other children, and lacked respect for teachers. And so this time, I told her (teacher) about this boy's experience. Then the surprise came when, some three months ago, the teacher told us that the child was going to school. He is not going every day, I think three times a week. The mother or the father stays with him at school, in class, so that the child can be quiet. She (the teacher) adapted the exams for him, but yes, I had the opportunity to see the exam and she gave him directions: 'colour the tree in green'. And the child coloured it green. This means that the child can already identify that it is a tree, the colours, the figures. And he is now starting to write some letters. He doesn't know all of them, but the teacher has taken the time, she had patience and commitment to dedicate more time to this child and to do a different exam for him, constantly adapting it to what the other children are learning. And so I believe it has been an achievement, because starting from there, from speaking about rights to teachers, opportunities have been opening up for all children of the community* (Group 2)

- CBR is providing efforts at working towards rights and to uphold these through campaigns, networking etc. This is supported by positive attitudinal change and political motivation among persons with disabilities and their own organisations:

> *New initiatives are emerging that they themselves have thought of. They want to form a regional network of DPOs….and to strengthen themselves, they are organising in a better way, and are forming part of political life, and some are aiming for political positions. They already feel capable of participating, each time more independently* (Workshop, Peru)

- It is bringing the discourse of rights to policy makers and others, and may be (slowly) influencing how these see persons with disabilities:

> *Before, there was talk about productive organisations, women…now they are talking about these but also about DPOs. Now the political candidates also talk about persons with disabilities, about the new law and its regulations* (Workshop, Peru)

- It is contributing to changing attitudes towards persons with disabilities, including within their families and communities and policy makers:

> *It is also about educating parents and other children so that they do not discriminate against them, so that they too start learning about equality in rights. And so it has been a process, but it has been thanks to the fact that we had the support of CBM* (Group 2)
>
> *CBR projects are for the community, and through it, one works and one goes on rehabilitating lives. At a community level, our work has a great impact since we already support a number of people in the community, and it influences them* (Online, Honduras)

- Provides guidance to persons with disabilities and their families and CBR workers provide accompaniment
- A point of contact and reference, including information especially for those in the most isolated rural areas:
- Sensitises authorities
- Strengthens emphasis on networks ('*redes*'), especially collaborations with local organisations working in different sectors
- A means of identifying needs, a sort of mapping exercise, and then developing a trail of interconnected services and programmes to accommodate these as they emerged: This excerpt from one of the focus groups captures this process succinctly:

> *Another very important aspect that contributed to the growth of the CBR strategy, was the work in networks, and the alliance among local organisations. That was also extremely important, and from this self-assessment tool- the three parts- emerged all programmes within the framework of the CBR strategy, we became aware that we needed an early stimulation programme, that would work in the community, we realised that we needed a school support program, we realised that we needed to organise self-help groups for young people that were in the home, and also the program of visual health, primary care for hearing problems. and so on the basis of this self-assessment, all other programmes emerged* (Group 3).

- Supports with locating and provisioning assistive devices and other equipment: support includes linking with other services and on occasion financial ones too.
- Generates knowledge among families and communities, politicians and others around disability, disability rights and other issues.
- Positive attitudinal changes among CBR workers: field workers and also managers expressed how working on the program had shifted their own

perceptions, uttering how they now saw persons with disabilities in a different light: as resilient people, with productive and social potential, and importantly human beings deserving of respect on an equal footing with others. Field workers expressed, and it was sometimes clear to see, how the sense of responsibility they felt towards persons with disabilities and their families extended beyond the duties of the job, developing caring relationships of friendship, a work they were committed to, and clearly not like any other:

> *It is certain that we are doing the work of the State. But as citizens, we have the obligation that people are treated equally, be they men, women, children, the elderly. Before starting to work in CBR, I had always looked at them (persons with disabilities) with pity, that many people still feel, because they are still not sensitized. We have to work on the theme of changing attitudes of authorities, schools. I believe that many things have been achieved* (Workshop, Peru)
>
> *Every morning, I now feel good, because the most important thing for me is to support these families, and this is what is of great interest to me* (Group 3)

4.3.2 Stories of Success

The stories of success shared were indeed many online and offline, including short visual narratives highlighting how many felt their work was not only having impact, but was contributing to CBR as a success story. We present a number of these below as they were shared with us as excerpts and vignettes. We feel they speak volumes on their own:

We visited people abandoned by their families, who are the subjects of mocking in their communities, all for being a person with a disability, of course without care, becoming simply another object. We took interest and we looked for professional support, we trained and we became volunteers, we looked for care, and in specific cases, we looked for financial resources for them, we donated adapted devices, wheelchairs and crutches... their parents changed their way of thinking and seeing their children not as an object but as one other member of the family, with the support of other organisations and professionals, providing training, also to the lifeblood that is the community, leaving behind greater sensitivity among the authorities, and they saw the need to build roads and be more sensitive. If we got to know more persons with disabilities, we would organise a meeting with them to inform them about their rights to inclusion, and once in the areas, they started to see that can fend for themselves and that they can do what others do. We are very happy that after so many problems and difficult situations, we can see that persons have become good people, who work, study, and leaders have emerged who are now he voice of those who did not have it, showing their leadership and they want to support them, they are very happy and that in our community the first DPO has been set up, and that for the first time a young person was included in school, and we can also say that work options, we can say, that God has been good and thanks to him, we are enjoying happiness (Online, Honduras).

Deaf youth in the community

Frank Molina Morey (20 years) is a young deaf man who lives in the district of Yántalo – provence of Moyobamba. His parents are separated and have other commitments, and two years ago he decided to move in with his uncles in the district of Yántalo. The hearing uncles have always been aware of the education of Frank ever since he was a child, they were aware that their nephew had to learn more and through friends they got to know that Asociación Paz y Esperanza is providing this education through special means for the deaf. When Frank joins the group of young people, he discovers a whole group of deaf friends who use their hands to communicate, in the beginning he was quiet and insecure when it came to responding or expressing an opinion, but over time he has shown much interest in learning.

Frank's interests were focused on learning sign language and on working, and even though the sign language team do not have this activity planned, like many young people, he felt the need to do something productive. The problem that young deaf people have is that they can't read or write, they know how to count but only at a basic level, and these lessons are not sufficient to be able to help him get a job, and so the family, through friends, started looking for a job that he could perform. The great advantage that Frank has, is his willingness to learn and to do a good job. During this time, he has been helping out in a carpentry, but then left to work in a bakery, and has discovered that has great skill when it comes to cake decorating and has begun to design them using his own ideas.

The managers are happy with the work of Frank, co-workers manage to communicate the daily tasks, and he has been working there for over a year now, and with his savings and the support of his uncles, has managed to buy a motorcycle taxi (vehicle to transport three people).

Frank has managed to enter the world of work through this opportunity that many other young deaf people do not have, many of them remain in their homes, working in agriculture, washing clothes for the parents or siblings, cleaning etc. This reality can only be changed when deaf people have access to a better education, and to achieve this, one needs to do very strong advocacy with our authorities so that they respect their rights and equality of opportunities just like a hearing person (Online, Peru)

The work we do in our CBR projects, are contributing in a great way, reaching remote places where parents do not find a solution to their needs, organising, training, empowering and rehabilitating. Awareness is another way in which we promote rights through campaigns at a community level, schools, health centres, etc. These actions have resulted in the integration of children in schools, community and political participation and the inclusion of young people in work... Our CBR projects have had a great impact on persons with disabilities, families and communities. When it comes to persons with disabilities, through comprehensive rehabilitation, rights of parents, through awareness and access to information... because when we work on CBR projects, we strengthen the community, providing services to the community in general. (Online, Honduras)

The following photo narratives shared by HOPAC in El Salvador highlight an impact that is very much aligned with the successes perceived in CBR, an impact that too is a process, is flexible and attentive to differences, that reaches beyond the person with disabilities:

Gimena Sanabria
Age: 12

At age seven, her life changed after a traffic accident, which left her with spinal cord injury. This means she cannot walk and mobilise herself in the same way. In the year 2010, she entered HOPAC, where she began the process of rehabilitation and started the education programme where she continued her first grade studies till this, and is about to start her fourth grade in the Centro Escolar Corazón de María having passed the grade with excellent results: "I want to be a doctor to help other children" is the phrase that Gimena utters now, and with her dreams she starts a new school day.

José Ángel García Fuentes
Age: 19

Diagnosed with Spina Bifida, he entered HOPAC in October of 2010, he joined the educational program where little by little, he started taking interest in his studies and in school, he began a process of educational levelling and then was included in the Centro Escolar Corazón de María, and is now about to enter third grade. He has excelled in singing and is determined to learn to read and count: "One must strive to study to have a better life" is the motto of this young man, who every day puts these words into practice.

Alex Granados
Age: 38

Alex has an intellectual disability. He is included in the vocational programme. Over time he has learnt to travel alone, contributed in all areas, but what he likes most is bakery, where he has excelled in creating bread recipes, developing very well. In the bakery 'Pan Carolina' at HOPAC he has been offered the opportunity to put into practice his knowledge, for him it is a challenge, and expresses how much he enjoys it and that his aim is to be punctual and less distracted. He states that being at HOPAC makes him feel very good.

Verónica Abigail Benito Pérez

Veronica is 20 years old, studied up to 8th grade, is a housewife and is dedicated to caring for her daughters. Mother of 3 girls, one of the twins has cerebral palsy due to complications at birth. For the mother, forming part of the chicken farming project has helped her in many ways, one of which is because before she was only focused on the care of her daughters, but today, makes time for entrepreneurship, which is the breeding and sale of chickens. This activity, according to her, serves her as therapy, as it has helped her do something else *and to destress. At home, the husband helps her take care of Veronica and her sisters, as well as with household tasks. Both she and her husband acknowledge that they are receiving income they did not have access to before.*

One participant in one of the groups recounted the trail of efforts to get one child into a special school, having to convince family and to mobilise a range of support, efforts she insists have well paid off:

> *There was a little girl from a distant neighbourhood, far from the special school…. She (field worker) had already gone to talk to the family so that they register the child at school and all that. And it was difficult because they did not accept... when we visited the family, a grandmother was caring for her... They were 25 yards away from the paved road where transport passed by… the special school. And so the grandmother told me: "It is that I can't get her to the corner, because she is in a wheelchair and one has to mobilise her all the way there and I am old, I can't". But she had a slightly older brother. So: "But the child can". So let's start: "Yes, but she has no uniform". "Then let's see how to get support for her so we got her the uniform." We go to the special school with her [the girl], with the field worker, and the special school principal helped us, shirt, backpack, and got her notebook, pencil. Indeed at the time she was not going to use it, but simply to encourage her. And we left. It was a thing of maybe three visits so that they integrate her. And I left the special school and now returned and there she was. And when she looks at me, she looks at me with emotion, because I insisted. And I tell her [grandmother]: "we will not leave her, we are going to continue to persist". And the grandmother agreed. And there was a way for them to mobilise 25 yards on the stone track to wait for the bus. The Director of the special school said to me: 'Tell me'. "We have already visited her... she took us to her house, and we did so with insistence". But it is as a way of encouraging her. Perhaps seeing that we were going find her what to get dressed with. The way we see it is that at that time, we were acting in a manner of handouts. But no, it is simply inclusion, and to then follow up, to go visit in the house, and then following up. And everything ok, she is now integrated in the special education school (Group 3)*

Successes are also reported as one transcends the CBR worker/person with disabilities relationship, to include the role of foreign CBR advisors, and the role they play in linking some individual cases with foreign donors (organisational and also individual ones). The support that can be provided is not only monetary, such as the case with operations and the purchasing of devices, but also innovative design for adapted devices. This means that these play a critical role in bridging services, as well as the financial and technical spheres. The following stories shared by CBR technical advisor Gonna Rota, based in Guatemala, are clear examples. Nixon, 16 years old at the time, was found with bi-lateral clubfeet in one project area. His lack of mobility was impacting all life areas, including education. With the financial help of individual foreign donors tracked by Gonna, Nixon was operated twice in 2014. Since the operation, he is not only walking, but has started to study again. Gonna reports how he is extremely happy and grateful to all who helped him to reach this. She explains how his eyes well up when he starts speaking about his feet now being straight. Below, Nixon's feet prior to operation, followed by photos of his recovery post-operation.

This is Nixon taking his first steps without shoes, a moment Gonna admits, was a very emotional one for everyone:

Other collaborations and linkages were reported, including that with institutions helping with design of assistive devices. The following standing frames for example were designed and provided by the Thayer School of Engineering at Dartmouth College (US). They were then assembled onsite in Guatemala and delivered to children with cerebral palsy:

Stories of success are indeed too many to document in this short space, and there are also many that remain unheard. We hope that this section simply provides vignettes highlighting the breadth of these perceived successes, but also offering spaces for further reflection. We round off this section with the story and journey of Alvaro in Nicaragua, one person with disabilities, of getting to know the CBR organisation, independence and eventually becoming a CBR worker:

ALVARO

(Written by Marion Muhalia, CBM Germany. Translated by Katharina Pfortner)

Throughout the week, I work as a community promoter for the CBR programme at ASOPIECAD, and Saturdays I am learning tailoring. For the time being I am sewing a pair of trousers for myself. For the material, the textile and the thread, I have received a grant from the government. A sewing machine costs US$200, but even without the sewing machine, after completing the course, I can work in a tailor's shop.

I got to know ASOPIECAD when I was 13 years old. I've been in a self-help group where I have learnt to sew and to make piñatas.

I was happy in the self-help group, because I was never alone. Being with others, I was happy. There, I've noticed that there is the possibility in ASOPIECAD of being an assistant community worker. That was my dream. That's why I've been talking with Erwin[5] and I went to the office once and then again, until they told me I could be an assistant. I like more to support children in learning to walk in the early stimulation program.

It is difficult to see some families. Some children or adults with disabilities want to be happy and they can't because they are not able to run or the family does not want to support them.

My own limitation is no longer not be self-sufficient, but not being able to read and write. My dream is to have my own family. "

Alvaro Enrique Vargos is 30 years old, he is a great man with a friendly, open face. He

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[5] Coordinadotor of the CBR programme at ASOPIECAD

has an intellectual disability, and he says it himself, how he can hardly believe it, because this life is still new to him and how he has fought hard for it.

Until the death of his mother two years ago, he rarely left the house. His mother did not hide Alvaro, as other families sometimes do with children with disabilities, but instead she protected him too much. She was always fearful that a car would run him over or that people would make fun of him.

Alvaro now lives with his sister Esmeralda. In the beginning, little changed for him: the brothers had promised his mother to take good care of Alvaro, and continued to forbid him from leaving the house and working. But Alvaro had a dream: he wanted to be a community promoter and get an education. He insisted stubbornly and finally his sister gave in and allowed him to.

Today Esmeralda is surprised: "we always overprotected him. Now we are very surprised by how well he is progressing in life. Everything was on his own steam, he organised everything'.

Alvaro as CBR assistant

We follow Alvaro and the CBR fieldworker Maryina Sequeira in their visit to Jonas (4). Jonas had surgery because his speech impairment had aggravated. With speech therapy alone, the desired improvement was not achieved. And so, he couldn't talk.

As from last year, Jonas has been receiving early stimulation. This consists in orientation and mobility activities, communication, independence and autonomy.

It is already the third time that Alvaro is here. They play together, Alvaro practices crossing the street with Jonas. Jonas' mother is delighted with Alvaro's work, Alvaro encourages Jonas and he has good ideas.

After the visit with Jonas, we move on to the house of Anselmo (16) and Miguel (23): "I went to the doctor and got him the ointment", says Alvaro as he greets the two youngsters and their mother. He bought the medication for the family, and he visits them frequently. The mother, María Anselma Martínez (58) is very happy about this. She has 16 children. Anselmo is her youngest. When he was 15 years old, he developed meningitis which resulted in a profound intellectual and physical disability. When Miguel was three, they diagnosed him with cerebral palsy.

Alvaro got to know the youngsters during an afternoon of sports that ASOPIECAD had organised. The self-help group had gotten a school bus so that the two youngsters could join. Given that they share a wheelchair and the track is not accessible, they had to push them, one after the other towards the main road, where the bus was waiting for them.

Alvaro is now their assistant when they go to the support group. He supports the youngsters in mobilising in the wheelchair, because the terrain is not accessible. He helps them with mobilising, playing, and much more.

An independent life

'Alvaro Enrique Vargos', writes Álvaro in my notebook, clumsily, but with no spelling mistakes. Alvaro was in a special school until he was 10 years old. There, no one believed that Alvaro would one day learn to write. But the teachers were wrong, they underestimated him and his abilities. Alvaro can teach them today- 20 years later- a good lesson. He has also managed to convince his family and he has shown them he can live an independent life.

During all the activities, one can see the pride Alvaro feels when it comes to what he is capable of doing and what he has achieved. Alvaro has reclaimed his right to an independent life, this is written in the UNCRPD too, and he has made his dreams a reality. Many persons with disabilities do not yet have this opportunity, to live life independently.

4.4 Factors and processes contributing to success

Working closely with participants in groups and building on that shared online, very constructive material emerged permitting a small window into the factors and processes participants felt contribute to success in CBR. Working within sub-groups, all three focus group participants explored and laid out what they saw as key factors, instrumental to CBR success within their respective contexts. I reproduce these in their entirety. It is reasonably easy to see that despite the breadth of points offered, there are quite a few common strands between these, notably: attitudinal change, commitment, openness, resources, alliances, flexibility, and support among others. I highlight these in bold for ease of reference and perhaps further exploration:

Group 2

- The **promotion of rights** through **community activities**
- CBM **support**: monetary and training
- Recognition and trajectory of the organisation
- Development, **synergy**, and experience to be able to scale up
- **Commitment** and responsibility on the part of the person, the person with disabilities and the family
- Credibility and transparency
- **Organisation and participation** by the person with disabilities and the family within this
- **Training:** of personnel but also for persons with disabilities and their families
- Sensitizing community
- Openings and coordination with **local governments**
- Involvement of the **family and the community**
- **Team** work
- **Quality** of work of CBR staff
- Opening avenues for **complaints**
- **Coordination** with private companies
- Use of **media** for promotional and informational purposes (radio, Facebook, web, TV etc.)

Group 3

- **Positive attitudes**: person with disabilities, family, personnel, private and state institutions:

  > *I believe that rehabilitation starts with the family. There are persons with disabilities who are just left in a room, and they do not even let them in to the living area. And so the family make them feel a little fear, grief, rejection, so rehabilitation begins from there, with the family, right from sensitizing the father, the mother, the person who is around, so that the person can get proper rehabilitation*

- **Good communication** with everyone
- **Training** and capacity building of various actors: It was clear at various junctures, that the best training comes from persons with disabilities and their organisations (DPOs) who can also work collaboratively with municipal and other authorities, to support, but also guide and monitor. This quote from the workshop in Peru supports this:

> *Yes there is empowered staff...we can. One must have a certain profile, we need to strengthen their capacities to have a comprehensive perspective. DPOs have to coordinate together with them and show them their reality, and also must not lose sight of children with disabilities (Workshop, Peru).*

- A united team, including mutual **respect and companionship**
- Development of **projects**
- Completion of objectives and plans
- **Funds**
- **Political and religious influence** in contributing to inclusive sectors
- Monitoring and evaluation
- **Constant accompaniment** of persons with disabilities and their families
- **Alliances**
- Legal framework
- National recognition of CBR and the organisation
- **Adaptation** to social and political changes
- Working with community leaders
- **Contextual knowledge**

Group 1

- **Awareness** at various levels, families, politicians, NGOs etc.
- **Strong, united and empowered DPOs**
- Support by the community, politicians, organisations and others
- **Training** and scholarships
- **Institutional alliances**: personal, professional, networks
- Availability and **openness** of the organisation
- **Empowerment** including of CBR workers (participation, management etc.)
- Personal and clinical **monitoring** and effective follow-up
- Not encouraging handouts: demanding a symbolic **contribution**
- Contribution to and **participation** by the parents and community in the programme
- Integration and sensitizing of **committed professionals** in the process (social workers, psychologists, occupational therapists etc.):

> *Also integrate committed professionals, and the participation of professionals in all areas. But, one must be sure they are already sensitized and involved in the area, because it is not the same to have a doctor who knows about disability and is committed as one who has the knowledge and who is totally committed to the cause.*

- **Formal government support**, especially local government
- Independence of the person with disabilities
- Empowerment of the person, including economic empowerment
- Self-esteem (of persons with disabilities)
- Positive psychological processes, especially among persons with disabilities
- A relationship of **trust** between the CBR organisation and the person with disabilities and his/her family and community

- Commitment from the CBR team
- **Better wages** for the team
- **Voluntary support**: making the most of voluntary labour

Observations such as these were corroborated by those participating online:

> *The factors and processes that we have found... for the success of CBR projects are unity, integration in the home as much as in society, also participation and community management are important factors that strengthen CBR projects* (Online, Honduras).
>
> *Factors such as recognising and accepting the problem of our children is essential for success in projects promoting integration both at home and in the community* (Online, Honduras)
>
> *In the case of CBR projects... it has been the empowering of community leaders and organisation of local committees that have helped to make persons with disabilities and other vulnerable people visible, and to draw in a comprehensive care and empowerment of their families. In CBR projects in Copan and Lempira, they attribute success to the management, organisation of communities benefitting persons with disabilities and processes such as job training have come to strengthen families and the communities themselves* (Online, Honduras).
>
> *Important is the strength of DPOs. Guidelines may be there, but you need the strength, the influence of DPOs, fathers, mothers. You need to empower so that they can reach this level... The State tries to divide people, so that they are not strong. You need the pressure of DPOs* (Workshop, Peru)

Reflecting further on these key points, there is much to be read into these, not least that key factors and responses to success are complex, multidimensional (socio-political, cultural, economic, ideological, and personal), require interconnectedness, responsiveness, and adaptability. The focus on monitoring and evaluation, on relationships and alliances that develop also suggest that success too is a process, that requires patient elaboration over time, and importantly reflection to be able to change what doesn't work. Furthermore, and linking these points back to the key common strands defining CBR, the inclusion of families and communities are key, and attitudinal change is the glue holding many of these efforts together.

4.5 Factors contributing to problems

All participants, online and offline worked and debated to also reflect on what they felt were the major problems they faced in their projects, and to consider the factors and processes they felt contribute to problems. It was immediately clear in the focus groups, that problems are many, cut across sectors, are multi-level (micro, meso and macro), and yet again multidimensional. Many are ever-present and enduring, with many in the focus groups suggesting these are what they battle every single day in their practice. They impact their work and more broadly the well-being[6] of persons with disabilities and their families. As with the section above I start off by reproducing the main points highlighted and articulated in the workshops verbatim:

Group 2

- **Lack of knowledge** about CBR at all levels: government, architectural design, businesses etc.
- **Families** resisting support and not collaborating
- **Culture of charity**: people expect handouts, including persons with disabilities and their families:

> *Culture of handouts among the population expecting more help. We are used to getting all we need handed out to us, and we believe in the organisations who come to knock on the door, it is because we take them something, and so even this.*

- **Lack of funds**: to be used for medical interventions and medical equipment among others
- **Inaccessibility and mobilising problems** e.g. roads impacting the ability to reach and work with families with consistence, as well as costs
- Lack of **public policies** and rights
- **Discrimination**
- Lack of **education** on disability in society
- High costs of adapted equipment
- Limitations, especially of resources in complying with the 5 targets outlined in the CBR matrix.

Group 3

- Lack of **personnel trained** in CBR and disability issues: including court, government, municipality, health services, schools and the private sector (e.g. policies on labour inclusion).
- Insensitive and ill-informed medical **professionals**: lack tolerance, have negative attitudes and need to be educated
- **Attitudes**: for example of school teachers and businesses (discrimination against persons with disabilities)
- **Poor infrastructure** and **climatic conditions (e.g. rain):** these impact the terrain, and limit the ability to mobilise and to reach and work with families
- Lack of **resources:** in particular material (e.g. vehicle) and financial resources
- **Migration** and relocation: for many of the poor, the priority is being able to survive. It is therefore difficult to follow up on the work and to give it continuity and there may be constant interruptions:

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[6] Well-being is a complicated and also contested term. Included in the conceptualisation here are broad components including, among others, accessibility, participation, and empowerment (social, economic, political and cultural).

> *The migration of families from one location to another due to lack of work opportunities. There are families we visit who have a child with a disability and the next day we visit, the child is no longer at home because the parents had to go to some other place...or... because manual labour was needed, or the mother had to go and work to be able to buy food for the children, or to take care of a farm estate... And then we do not know where the child is. And suddenly a few months later or the following year, the child reappears. And so it is this, having to look for them, and at times there are other children here, and without any progress because the child cannot be supported... the greatest need for them (families) is to take food home. And working in places that are too far away, limits them when it comes to other priorities they should have.*

- **Limited time** (family and even the person with disabilities) to engage because of work commitments: these interrupt CBR activities and also condition the frequency with which they can be executed:

> *Also if they go to a farm, then the child is taking care of the chickens on the farm, and the mother and father are milking the cows, and the mother taking care of the pigs. It depends on the activity they are involved in on the farm, the owners, because they work for other people. Sometimes the child also goes with a machete, or the young person with a disability is working with a machete in agriculture (Group 3)*

- **Parental issues:** including attitudinal problems and lack of financial resources.
- Lack of **knowledge** including of rights by families and persons with disabilities themselves
- **Climatic conditions** e.g. rain- these affect mobility and accessibility, including the ease with which children can reach schools
- **Financial resources**: including for salaries and materials of the CBR workers themselves.
- **Transportation** problems and costs
- **Municipal budget** for disability

Group 1

- Lack of **leadership**
- Attitudes of persons with disabilities, families, community etc. These include: overprotection, indifference, lack of care, but also dependence by the person with disabilities
- Lack of knowledge of **indigenous languages**: this requires training within the same communities
- Lack of education of the person with disabilities and the population at large, especially non-formal education
- Lack of **training** among personnel
- **Lack of funds:** for the organisation as well as the person with disabilities (e.g. to pay for transport to reach the services)

- **Lack of sustainability:** funds are tied to temporal projects, year after year with little or no knowledge of whether projects will be continued, who will work on them and so on, creating feelings of insecurity as well as instability (see below):

> *Yes, dependence on projects and there is a lack of sustainability. But: what happens when they approve a project for us for this year, but next year there are no funds, what do we do? There is neither transfer of knowledge nor empowerment of the organisation.*

- Disability is **not a priority sector** among authorities:

> *To the authorities and all those, persons with disabilities are regarded as a non-priority sector, i.e. it does not interest them alot, they regard it as a sector of "let's see what happens"*

- **Lack of public policies**
- **Changes in local government**: headway done with a local municipality is lost when another one is elected:

> *What affects is also the change in local government, because the mayor changes and you have to go explain all over again all the story, and it like starting all over again.*

- **Lack of awareness** by community leaders, including of work being done by CBR organisation
- **Lack of coordination and cooperation** e.g. between the organisation and council for development
- Lack of physical accessibility to certain areas
- **Too many tasks and functions** to be performed by the staff:

> *The health sector should have personnel for rehabilitation. But the field worker has to do other activities in areas of social communication* (Workshop, Peru)

- **Religious and other beliefs and psychological impacts:** influence not only how disability is perceived but also if and how they engage with CBR:

> *The practice of the Catholic and Evangelical Churches here is that they go to parishioners' houses, but instead of encouraging you and all of that, it is like 'we are going to give you something because it is God's will', and so they reinforce certain concepts, instead of pulling you out of there, they reinforce those concepts.*

Other, perhaps more subtle factors and processes emerged, including the fact that:

- CBR may be **alleviating or removing responsibility from the government** to the extent that the latter does not feel responsible for persons with disabilities
- CBR is sometimes **perceived as lacking quality or of bad quality** (see above) and **a cheap alternative,** especially by government**:**

> *... another example of this bad quality is, for example, the belief that CBR too is a project that does not need much money, that it is poor. Because this, yes, I have heard it and have seen it on other areas. That it is poor, and that we have to use resources that exist in the community and all that.*

Yet again, other narratives, including those online, reflect these and also build on other concerns, including political, economic and informational bottlenecks:

> *Just as there are factors that are important for success, there are many others that cause difficulties in our projects, e.g. apathy by the authorities, teachers, parents and society itself, another factor is the lack of information about laws, given there are many cases of parents who do not demand the rights of their children because they do not have this type of information* (Online, Honduras)

> *In CBR projects, we agreed that the factors causing difficulties in projects have been policy, the lack of financial resources for operations, the lack of awareness of decision-makers* (Online, Honduras)

> *Authorities are products of society, they are not trained, they have a very medicalised perspective, one of charity, and to change this, there need to be stronger exchanges, but also with political guidelines* (Workshop, Peru)

> *It is certain that as CBR, we are doing the work of the government, but in this country there is so much indifference, and so many people in a state of vulnerability. It is somewhat difficult, you know, in January after the elections, everything changes, in July again change of personnel and it is always like this, and this is how the work of sensitization goes* (Workshop, Peru)

…and even religious partisanship and separation emerge as problems on occasion:

> *In Mexico, the partisan and religious issue has divided and fomented severe aggression between groups, the field workers who have not demanded payment are always people who have a field worker with some religious inclination or partisanship, and this ethically goes against the CBR practices* (Online, Mexico)

Organisations reflected on more immediate issues and needs within their own organisations, articulating in the process, other challenges:

- creating material, especially narrative-style material that can communicate with and reach funders to showcase their work
- structuring proposals for funding
- communicating and establishing relationships with policy makers and accessing small pots of money

- paying wages securely and in a sustained way and employing more field workers: One organisation with no funds to pay fieldworkers (promoters), reflects on this critical issue:

  We have never had funds from anyone to pay our field workers and because of this we haven't followed them because 'hunger is desperate' (saying) (Online, Mexico)

- sustaining their projects over time and contributing to genuine well-being and independence:

  Independence also involves facilitating opportunities, resources. Because not only... I can tell someone to be independent, but I also have to give him/her some resources so they can move on for example, or a chance to work, training, I don't know, because independence is so interconnected, because you cannot become totally independent because money is always lacking (Group 1)

To reiterate a key point in this report, and much echoed by participants in the three workshops- CBR costs money. This does not mean it is more expensive than other interventions (if any are present at all), but like any other programme, it needs funds to operate, whether to pay wages, rent or purchase materials. It also points the discussion towards the need for other, and perhaps more viable solutions, including those of paying field workers through local government or sectoral funds. To be clear, CBR organisations demonstrate extraordinary resourcefulness in looking for diverse and alternative sources of funding in order to not depend on any one pot at any one time, and this includes CBM. One example of many is the resourcefulness of organisations such as AGAPE and its leading priest in El Salvador. Hosting also the CBR programme, the extensive AGAPE space also includes a hotel, a restaurant, and conference space. Using careful and effective branding, AGAPE also offers medical packages, including cataract operations, medical intervention and lodging included. CBR seemed to be nestled within a broader and strong business model. Other organisations, though, on a much smaller scale, try to devise strategies, including getting local politicians to endorse and contribute to funding a part of the project; charging a nominal fee for services; and producing and selling artisanal products. Nevertheless, preoccupations about sustainability of programmes, and the insecurity of not knowing whether CBR field workers will have a job from year to year, appeared to be consistent among all participants. Financial security appears to be a key problem for most, because funding, as it seems, is erratic, not all politicians are interested in building up and taking over CBR programmes, and poor families can only contribute little in the way of payment for services. In one group, fieldworkers complained that they did not even have sufficient paper to write their notes on. In this same group, they also commented about the desperate need for a vehicle or motor cycles because accessing the field was becoming more and more difficult and erratic.

Human resources are key in CBR. They are the fulcrum of CBR, and as I witnessed in workshops, CBR workers are very passionate about what they do. Many have been and continue to work in CBR for a reasonably long time, with love, commitment and dedication to promoting the well-being of persons with disabilities and their families.

Conversations with advisors highlight how overall, turnover appears to be low. But, like everyone else, CBR workers, especially the field workers are trying to piece together a living and need to survive. Many may also have their own relative poverty to deal with. While it is impossible to generalise across the board, in practice, most of these CBR workers do not work on a voluntary basis. Furthermore, these do not seem to be well-paid jobs, and wages are contingent on funding. Overall, these issues deserve some attention, not least because they may have some implications for practice. To be clear, low pay and the struggle to survive do not mean lack of commitment or low quality work, or that the work is simply done for money. Far from it. Nevertheless, lack of job security and low wages may well affect staff turnover over time, or perhaps even demotivation or fear of dismissal. Again, this is a subject for further research and that can only be adequately explored longitudinally, but which still opens a space to look more closely into other issues, including those of programme and staff longevity.

4.6 Gaps: the reality facing persons with disabilities

While the perceived impacts of CBR map out laudable achievements and successes, the road remains a long and winding one, with many gaps and needs along the way. The reality facing persons with disabilities is too often one marred by profound and enduring poverty as well as exclusion from various spheres of life. This is where disablism and poverty are lived out, not only by persons with disabilities, but also by their families (see Grech, 2015). This, to those participating online and offline, made CBR not only relevant and needed, but also a continuous struggle, one of constantly trying to defy odds:

- Gross unemployment and inordinate barriers to work for persons with disabilities translating into lack of money, low self-esteem and even compromised survival. Barriers are also attitudinal, much of which a result of lack of knowledge around disability:

  > *Because of this lack of employment, the economic aspect, money… If they do not have money, they cannot reach the place where they provide physiotherapy or they do not have money to buy a pair of orthopaedic shoes for example* (Group 2)
  >
  > *We cannot go to work at this company, because if the employer does not have knowledge of CBR, is not trained, does not know, then they too will discriminate against persons with disabilities. And they do not offer an opportunity of employment.* (Group 3)
  >
  > *In the area of subsistence, we have difficulties, because the business group is not sensitised. It suffers from great stigma when it comes to disability and is well hard. It is a challenge to work in the area of subsistence* (Workshop, Peru)

- Lack of educational possibilities for persons with disabilities on account of untrained teachers, and attitudinal concerns, but also lack of materials alongside other problems. These are accentuated for those in rural areas:

> *All the schools, if we speak of ramps, there are only two, three schools that have them... the majority of teachers do not know much about disability. If a child gets to school…if the child is in a regular school. But the child is in the corner, the teacher does not speak to him/her, his/her classmates insult the child... they even told me... 'it is because your students are ghosts'* (Group 1)

> *For example, a child who is deaf can't function in a school, because we are still in the process of inclusion. A child who is blind, there is no braille... the attitude of teachers is that if they see a child with Down's enter a classroom, the first thing they do is to put him/her in a corner, and they don't have a proper curriculum, they do not do adequate activities for the improvement of this child. Even if they are trained. At times, the easiest thing to say is: "It is because we do not know how to do it".* (Group 3)

Within this scenario, participants in two groups expressed reservations about the possibility of 'inclusive education' and how in the meantime, and in the midst of this imported discourse, special schools and dedicated services may still be the best alternative when facing concrete barriers:

> *Even if that teacher is trained, he/she is not doing anything for that person with a disability. Although there is much talk of inclusive schools, but even if you have trained staff... not everything is put into practice. It is like the law, the law is there, but what happened with the law, is it fulfilled?* (Group 3)

> *I am in favour of inclusive education, but I think that the educational community is not yet ready to cater for people with different disabilities. So, I think and believe, that specific services must be available and support in everything so that persons with disabilities are included in these environments* (Group 1)

- Rights violations
- Services lacking personnel
- Deep barriers to health care and rehabilitation
- Inaccessible or inexistent services, including benefits, compromising survival
- Poor, unhealthy and dangerous living and working conditions
- Lack of or no money for services and equipment and maintenance of these.
- Infrastructural design executed without persons with disabilities in mind and profound infrastructural and architectural hurdles
- Constrained physical mobility on the harsh terrain
- Limitations in services offered by organisations, including ones working in CBR (on account of lack of funds and resources in particular)

- Negative intra-familial attitudes including lack of support, discrimination and lack of acceptance
- Attitudinal problems by the person with disabilities him/herself (e.g. dependence) as well as family (e.g. overprotection)
- Insensitive or indifferent politicians
- Lack of connection between CBR and disability councils
- Extreme and chronic poverty experienced by whole families

While policies and treaties are not scarce, the rhetoric-action gap remains wide, when laws, rights, and policies meet and face real life:

> *Peru is 'super capable' of making laws, but these laws are only for those who are in power. We, as persons with disabilities, who are not educated, who have not had the opportunity to study, no, and that hurts me alot. But the rights are for those who are on top, in power. Programs never reach the poor. In San Martin, without having CBR, we would have disappeared. It is important that CBR visits children so that they can go to school, so that they can have an assessment. But you have to go with them, because in other areas, they are still hidden (Workshop, Peru)*

Stories, including personal ones, appeared to highlight a trail of unattended needs and even frustration, but rarely losing hope that things can change in the future. And indeed they also mark out how CBR has a continuing role in counteracting this situation and perhaps closing the gap, even if provisionally. Those working with the facilitator in all the groups reflected backward but also forward on what they would like to see, and what they feel needs to be done. I list these as they were articulated within two of these respective workshops, while building up analysis on some key points:

Group 2

- Sensitize and inform communities
- Tools and equipment for schools and training, for example a speech and language teacher
- Train CBR personnel (e.g. sign language)
- Training to be able to replicate practices in communities: a problem in the training process, participants expressed, is the fact that the capital city is too far and costly to reach.
- **<u>Funds</u>**
- Prostheses, especially auditory: the process is haunted by a range of bureaucratic and communication problems
- Physiotherapist and a psychologist
- Self-support groups in the community
- **<u>Vehicle</u>**: reaching project areas, especially distant rural areas remains notoriously difficult, time consuming, and erratic

Group 3

- **Resources**, especially funds to execute projects, buy materials, pay wages and keep projects running with regularity and consistency
- Office materials
- Lobby policy makers and service providers:
- A vehicle: notably a motorcycle to be able to get into the rural areas and reach families with ease and time-efficiently

The issue of funds has been amply highlighted in the sections above. All three groups also reflected further on the issue of sustainability, and one key concern was how to ensure their work can extend over time. They (project managers in particular), insisted that the need to look for varied sources of funding, was a persistent worry and concern. Solutions accompanying this, included finding ways of making their work more visible to potential funders, for example by using social media. Most of the managers present suggested the need to structure proposals and submit these to specific donors. Nevertheless the process of searching for, contacting donors, and applying for funding, as in many other contexts, is long and arduous, and requires skill, time, and resources that may not always be available without adequate support. One group appeared well organised, connected and structured to handle this process, but it remains an open question as to the extent to which application for funding may require injections of external technical and even financial support. Another group highlighted how leaders with disabilities are also needed, to take control, to give CBR continuity, and that their role was that of providing capacity building and empowerment and opening spaces for political participation and to influence key stakeholder such as the councils:

> *… it is about beginning to train persons with disabilities who are leaders, because it is there that it happens we feel, the whole issue of sustainability, one is the training of leaders so that they are empowered and participate in these spaces we have already talked about, of community councils, development councils, until reaching the departmental council. The issue is that it is not the same thing that I talk as when a person with a disability talks... right now we are turning things on their head, we are integrating persons with disabilities in that space, for their training, for their empowerment, so that it is they who participate at this level* (Group 1)

Filling the gap also requires training, a word that featured prominently among all groups. Training is a major problematic when it does not come in sufficient amounts, is not cost-effective and tailor-made (e.g. to time requirements) and/or is not of high quality enough to impact performance but also to stimulate employability. Training, participants stressed, is needed to empower CBR workers in refining their practice but also to stimulate employability. It was interesting to note the difference between training needs articulated by managers and field workers. While the former were more interested in policy and programme development and promotional skills, the latter emphasised their immediate skills affecting directly their work with persons with disabilities and their families, skills they could carry forward. I present these as articulated by participants:

Coordinators:

- Training on the CRPD especially legal aspects, including national policies
- Elderly and disability
- Didactic tools
- How to facilitate work insertion
- Techniques on how to reach out to and educate teachers and schools:

> *We have the skills, we are doctors, we are trying to make it as best as possible, but we do not reach the teachers to be able to give them the methodological tools needed on how best to assist a child with a disability* (Group 2)

- Small business and livelihoods
- Funding: see above- from searching to applying for funding, these are skills that are often lacking.
- Marketing of work: important for visibility but also to tap into funding. This includes effective use of narratives.

Field workers:

- Sign language: this was uttered frequently and with emphasises, suggesting it would increase reach in fieldworkers' operations, but also enable them to work with a population they struggle to include in their work.
- Braille: some participants claimed that teaching Braille to persons with disabilities was necessary, but that they had a role to offer if they could learn about it too.
- Technical training: this included various things: rehabilitative techniques; basic physiotherapy; report writing; basic knowledge on different impairments (including signs); technical tips on how to work with each person individually; the social aspects of disability; self-help skills among others.

All participants went on to articulate, though, how training was needed not only for themselves, but also for others, including families, policy makers, schools, and the community at large, in order to have a multiplying effect. These covered a range of areas such as:

- Basic knowledge of different impairments for teachers
- Update on the CBR guidelines for everyone
- Sensitize family, children and others about disability in other departments to have more coverage, including of CBR
- Micro finance management training for the person with disabilities and the family
- Disability training for policy makers and service providers as well as professionals such as doctors and therapists, in particular the social conditions.

The following quote captures the need for this training:

> *We believe it is families who can really replicate knowledge with other families, it is them and persons with disabilities in communities who are the multipliers and also who affect local policies, and for them they need training and in a permanent way because the challenges change* (Online, Mexico)

Overall, emphasis was made on training that is flexible but that evolves, implying that participants were keen to seek incremental training they could receive over time, and that this, just like CBR, was a process.

4.7 Looking forward: Hopes and Dreams

Those in the focus groups were asked to reflect on the past and present and to look forward towards the future, to express how they felt, what they saw, and what they hoped to see and do. This opened the space further to look at hopes and dreams. I present these verbatim, fusing those articulated in the three workshops to link them together, perhaps as a CBR road map, a collective trajectory of hope and change, but still generated by individual voices- a reality that many want to see:

- Change of attitude in families and communities to include the person with disabilities so he/she does not feel different
- Enhance knowledge and teach young people and others, including doctors
- Moving CBR closer to the home and away from central hubs
- That CBR would be a reality for everyone, especially those who do not receive any service
- That all children can go to school and learn how to read and write with a patient teacher
- Study to become a therapist
- See independent persons with disabilities
- A model of CBR that is sustainable and not needing any more external help
- That persons with disabilities can find sources of employment
- Achievement of persons with disabilities' rights in their entirety
- More inclusion to be able to live peacefully
- More disabled leaders
- Development of different functions for the organisation, including monitoring and evaluation
- To become a foundation and expand
- To shape public policy
- Continue studying to be able to support persons with disabilities
- See a mother working
- That persons with disabilities determine their own destiny

5. Some concluding remarks and lessons learnt

This report made use of reflection and narrative to listen to the voices and perceptions of some CBR colleagues and friends. This is far from a complete exercise, and like any other small project, packed with its own gaps, doubts, and spaces for development by others. Nevertheless, there is much to learn. Distilling the themes in this report is hard and perhaps would not do them justice, but I offer some concluding remarks, which, I hope could serve for further reflection, and perhaps, research. Importantly, they are some lessons learnt over the space of this project:

- CBR is perceived to have numerous benefits by those working in it, spanning the social, economic, personal, and political spheres. Benefits reach out beyond the individual to include family members, field workers, and also communities. It also makes strong contributions in changing attitudes towards persons with disabilities (including among families) and has positive psychological dimensions.
- CBR is multidimensional, fluid and dynamic and hence cuts across time, space and sectors, and demands collaboration and action between a range of stakeholders.
- CBR cannot be standardised, and in this respect, the Latin American space too may well have its own heterogeneous needs and responses to immediate contexts and demands. These voices need more prominence, to be heard, listened to, and then to again acknowledge the heterogeneity of these. In this regard, while the guidelines provide much support in providing roadmaps and articulating dimensions for attention (among others), they may also be limited when it comes to very specific micro ‘conditions’ and circumstances.
- CBR is an ongoing project where the person with disabilities is at the centre, a process firmly linked to family and community, and which is strongly impacted by attitudinal and other concerns.
- CBR as a process means it is constantly changing and adapting, and hence demands flexibility and responsiveness to change. CBR develops contextually and circumstantially. The implication is that impacts can only be evaluated over time, and that research attempting to evaluate CBR, cannot do without taking a long view.
- CBR is clearly tied to rights and the propagation of these, sometimes as a logic and background, and at other times, as an end. Nevertheless, this relationship is far from linear or clear, and demands further research exploration. While CBR, the CRPD, national disability policy and the rights language are clearly connected in discourse, the connections with practice demand further questioning.
- Understanding the internal workings of families and communities is key, and working closely with them determines if and how the programme develops, the support activated, and more importantly, the well-being of the person with disabilities.
- Various perceived factors and processes determine impact and reach of CBR. Of note, are funding, personnel, but also linkages, alliances and collaborations with

others, starting off from families and communities, to service providers, policy makers, and other organisations.

- Persons with disabilities face harsh conditions, including poverty and political indifference, sustaining the need for CBR over time.
- Issues of effectiveness, impact, reach and sustainability (among others), are topics for further research, and to reiterate, one that can only be adequately evidenced and documented over time through larger longitudinal studies, prioritising the voices of persons with disabilities and their families. Research into the factors and processes contributing to problems in CBR, would be helpful in identifying, anticipating, and making adequate (but flexible) arrangements for such concerns and to boost the factors that facilitate success in specific contexts.
- CBR needs money: lack of secure resource flows (in particular financial) may compromise reach as well as sustainability. The findings direct attention towards involvement of others in CBR, including organisations, but in particular local governments, and their role in promoting and supporting more sustainable CBR projects. They have a key role as connectors, but also as potential funders and also co-implementers. Disability is ultimately everyone's responsibility. Findings also suggest the need for investment in CBR workers, in skills, but also equipment and financial resources. Research would be helpful in identifying further the association between CBR and funding, bottlenecks in funding, gaps in the process (including capacity building), with a view to exploring a range of options.
- CBR and those working within, look positively towards the future, in particular when it comes to seeking strategies and solutions that may contribute to the empowerment and well-being of persons with disabilities and their families. These strategies need to be heard, learnt from and built on to make for genuine bottom up learning. These are the real 'experts'.

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