

MARIE GRANDISSON

**DEVELOPING GUIDELINES
FOR PROGRAM EVALUATION
IN COMMUNITY-BASED REHABILITATION**

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School of Rehabilitation
Faculty of Health Sciences
University of Ottawa
Ottawa

Abstract

Community-based rehabilitation (CBR) is an inclusive community development strategy implemented for and by people with disabilities in resource-poor areas. The scarcity of guidelines for CBR program evaluation largely contributes to its insufficient and fragmented evidence base. This thesis aimed to advance knowledge in this field by defining best evaluative practices in CBR and developing guidelines to foster sound CBR program evaluation. To achieve this, the doctoral candidate designed a sequential mixed methods study in three research phases: 1) a systematic literature review to identify potential best practice guidelines, 2) a field study in South Africa to pilot the guidelines, and 3) a Delphi study to generate expert consensus and refine the guidelines. Findings from this doctoral research emphasize the importance of giving a voice and control to those most affected by the program throughout the evaluation process, including people with disabilities. The findings also call for embracing the challenge of diversity by adapting CBR program evaluation to local cultures and languages, and by ensuring that programs leave no one behind. In addition, they indicate that CBR evaluators can foster the use of process and findings by endorsing a rigorous, collaborative and empowering approach. Ten best practice guidelines for CBR program evaluation were systematically developed through the three phases and represent expert consensus. They offer much-needed directions. Three represent features of sound CBR program evaluation processes, six offer indications to facilitate sound methodological decisions, and one recommends using a common framework to situate evaluation findings. The guidelines now need to be piloted in a range of CBR contexts and linked with tools to yield the valid and reliable data necessary to establishing CBR's evidence base and ensuring that program evaluations lead to positive change in local communities.

Keywords: community-based rehabilitation, CBR, evaluation, program evaluation, guidelines, methods, process, framework

Résumé

La réadaptation à base communautaire (RBC) est une stratégie visant le développement communautaire inclusif des personnes ayant des incapacités. Le manque de lignes directrices sur l'évaluation de ces programmes explique en grande partie que les données probantes sur leur efficacité soient insuffisantes et fragmentées. Les objectifs de cette thèse étaient donc d'ajouter aux connaissances sur les meilleures pratiques d'évaluation de programmes en RBC et développer des lignes directrices sur ce sujet. Une méthodologie mixte en trois phases a permis d'y parvenir : 1) une recension systématique de la littérature pour identifier les meilleures pratiques répertoriées, 2) une étude pilote en Afrique du Sud pour maximiser l'applicabilité des lignes directrices, et 3) une étude de type Delphi pour générer un consensus auprès d'experts en RBC et raffiner les lignes directrices. Les résultats témoignent de l'importance de donner la parole et le contrôle de l'évaluation aux personnes les plus touchées par le programme, incluant celles ayant des incapacités. Les résultats accentuent également la nécessité d'accueillir la diversité en adaptant les évaluations aux contextes culturels et linguistiques, et en s'assurant que les programmes soient inclusifs. Ils indiquent aussi qu'une approche rigoureuse et collaborative dans laquelle les capacités locales sont consolidées favorise l'utilisation du processus et des résultats d'évaluation. Le groupe d'experts est arrivé à un consensus sur chacune des dix lignes directrices développées pour l'évaluation de programmes en RBC. Trois de celles-ci touchent les caractéristiques essentielles du processus d'évaluation, six soutiennent de bonnes décisions méthodologiques, et une suggère que les résultats soient présentés dans un modèle commun. Ces lignes directrices doivent maintenant être validées dans plusieurs contextes et associées à des outils facilitant leur application. Cela permettra de générer les données valides et fiables requises pour établir des données probantes solides en RBC et s'assurer que les évaluations engendrent un impact positif dans les communautés impliquées.

Mots clés : réadaptation à base communautaire, RBC, évaluation, évaluation de programmes, lignes directrices, méthodes, démarche, modèle

Table of Content

Abstract.....	ii
Résumé	iii
Table of Content.....	v
List of Tables	viii
List of Figures.....	ix
List of Abbreviations	x
Preface.....	xi
Acknowledgements	xiv
Chapter 1: An Introduction to Community-Based Rehabilitation	1
1.1 The Issue of Disability: Why Does it Matter?.....	1
1.2 CBR: Its Beginnings, Current Definition and Core Principles.....	2
1.3 Emergence of a Conceptual Model: The CBR Matrix.....	4
1.4 Effectiveness of CBR: Is it Working and Under Which Conditions?	6
1.5 Conclusion	11
Chapter 2: Thesis Statement: How Should CBR Programs be Evaluated?.....	12
2.1 Knowledge Gap: The Scarcity of Guidelines for CBR Program Evaluation	12
2.2 Research Questions	13
2.3 Objective: To Define Best Practices in CBR Program Evaluation.....	14
2.4 Definition of Key Concepts.....	14
2.5 Methodological Overview	15
2.5.1 Background: How are guidelines developed and what influenced my choices?	16
2.5.2 A sequential three-step process to develop guidelines for CBR program evaluation.	17
2.6 Ethical Considerations	19
2.6.1 Respect for persons.	20
2.6.2 Concern for welfare.	20
2.6.3 Justice.	21
2.7 Conclusion	21
Chapter 3: Using the Literature as a Starting Point	23
3.1 A Systematic Review on How to Conduct Evaluations in Community-Based Rehabilitation – FIRST ARTICLE	24
3.2 A Review of Suitable Program Evaluation Approaches: What Can CBR Learn from the Evaluation World?.....	36
3.2.1 Empowerment evaluation (Fetterman & Wandersman, 2005).	36
3.2.2 Transformative evaluation (Mertens, 2009).....	37
3.2.3 Utilization-focused evaluation (Patton, 2012).	38
3.2.4 Health program planning and evaluation (Green & Kreuter, 2005).	38
3.2.5 Framework for program evaluation in public health (CDC, 1999).....	39
3.2.6 Evaluation Hierarchy (Rossi et al., 2004).	40
3.2.7 Theory-driven evaluation (Chen, 2005).....	41
3.2.8 Real-World evaluation (Bamberger et al., 2012).....	41
3.2.9 Social Analysis Systems ² (Chevalier & Buckles, 2013ab).	42

3.3 Initial Proposition for Best Practices in CBR Program Evaluation	43
3.3.1 Key features and steps for CBR program evaluation.....	43
3.3.2 Using a framework in CBR evaluation.	48
3.4 Conclusion.....	49
Chapter 4: Community-Based Rehabilitation Program Evaluation:	
<u>Lessons Learned in the Field</u>	<u>51</u>
4.1 Community-Based Rehabilitation Program Evaluations:	
Lessons Learned in the Field – SECOND ARTICLE.....	55
4.2 Why Did I Make these Methodological Decisions?	73
4.2.1 Reasons for favouring perspectives of parents, staff members and managers.....	73
4.2.2 Participant’s recruitment and participation.	73
4.2.3 Consent documentation.	75
4.2.4 Rationale for using a journal and suggestion boxes.....	75
4.3 Conclusion.....	76
Chapter 5: Community-Based Rehabilitation Program Evaluation: Generating Consensus	78
5.1 Expert Consensus on Best Evaluative Practices in Community-Based Rehabilitation	
- THIRD ARTICLE	79
5.2 Additional Information on Panellists’ Opinions	92
5.2.1 Explanations on the criteria for sound CBR evaluation processes.	92
5.2.2 Data collection methods panellists would most likely use and why.....	93
5.2.3 Strategies to foster a good community-method fit.....	95
5.2.4 Pros and cons of potential shared frameworks for CBR evaluation proposed.....	96
5.3 Conclusion.....	97
Chapter 6: Best Practice Guidelines and Model	
<u>for Community-Based Rehabilitation Program Evaluation.....</u>	<u>98</u>
6.1 Main Lessons Learned in the Three Research Phases.....	98
6.1.1 Main lessons learned in Phase 1: Literature review.....	98
6.1.2 Main lessons learned in Phase 2: Field study.	100
6.1.3 Main lessons learned in Phase 3: Experts consultation.....	101
6.2 Best Practice Guidelines for CBR Program Evaluation.....	103
6.2.1 Guideline 1: Participatory evaluation process.	108
6.2.2 Guideline 2: Empowering evaluation process.	108
6.2.3 Guideline 3: Embracing cultural diversity in the evaluation process.	110
6.2.4 Guideline 4: Using a shared framework to situate evaluations.....	111
6.2.5 Guideline 5: Being inclusive of all voices during data collection.	115
6.2.6 Guideline 6: Favouring mixed methods.....	116
6.2.7 Guideline 7: Favouring participatory tools to collect data.....	117
6.2.8 Guideline 8: Using tools that closely fit the purpose.	118
6.2.9 Guideline 9: Alleviating the impact of linguistic differences.	119
6.2.10 Guideline 10: Combining universal and context-specific indicators.	120
6.3 Best Practice Model for CBR Program Evaluation	121
6.4 Conclusion.....	124
General Conclusion.....	127
References.....	133

Appendices.....	145
Appendix A: Publishers' Permissions to Include Articles.....	145
Appendix B: Ethical Approval.....	150
Appendix C: Consent Forms.....	152
Appendix D: Discussion Group Guide	158
Appendix E: Round 1 Invitation Email to Experts.....	160
Appendix F: Round 1 Questionnaire for Experts	162
Appendix G: Summary of Round 1 Findings	173
Appendix H: Round 2 Invitation Email to Experts	176
Appendix I: Round 2 Questionnaire for Experts	177
Appendix J: Summary of Round 2 Findings	185

List of Tables

Table	Title	Page
1.1	Main themes represented in the core principles guiding CBR	4
2.1	Definition of key concepts	14
3.1	Real-World evaluation strategies to address evaluation constraints	42
3.2	Key features of best practices in CBR program evaluation	45
3.3	Steps in a CBR program evaluation process	46
5.1	Data collection methods panelists would most likely use	93
5.2	Panellists' perceptions of the pros and cons of the frameworks for CBR evaluation proposed	96
6.1	Best practice guidelines for CBR program evaluation	104

List of Figures

Figure	Title	Page
1.1	The CBR Matrix (ILO, UNESCO, & WHO, 2004b)	5
3.1	The Evaluation Hierarchy	40
3.2	Initial model for best practices in CBR	47
3.3	Initial proposition: Common framework for CBR evaluation	49
4.1	Logic model: <i>Goedgedacht</i> 's early childhood development project	53
6.1	Shared framework for CBR evaluation	114
6.2	Simplified shared framework for CBR evaluation	115
6.3	Best practice model for CBR program evaluation	123

List of Abbreviations

AGREE	Appraisal of Guidelines for Research & Evaluation
CBR	Community-based rehabilitation
CIHR	Canadian Institutes of Health Research
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled people's organization
ICF	International Classification of Functioning, Disability and Health
IDDC	International Disability and Development Consortium
ILO	International Labour Organization
JPS	Joint Position Statement
FASD	Foetal alcohol spectrum disorder
NSERCC	Natural Sciences and Engineering Research Council of Canada
NGO	Non-governmental organization
PAR	Participatory Action Research
PRECEDE- PROCEED	Predisposing, Reinforcing, and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation – Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development
SAS ²	Social Analysis Systems ²
SSHRCC	Social Sciences and Humanities Research Council of Canada
UCL	University College London
UN	United Nations
UNESCO	United Nations Educational Scientific and Cultural Organization
WB	World Bank
WHO	World Health Organization

Preface

In September 2010, when I began my doctoral degree, I wanted to learn more about community-based rehabilitation (CBR) and to advance knowledge in this field. My supervisor (RT) had received a request from a South African non-governmental organization (NGO) to evaluate its CBR program and asked me if I was interested by this project. I accepted, but I quickly realized that there were very few guidelines on the best ways to evaluate these programs, even with the publication of the *CBR Guidelines* in December 2010 (WHO, UNESCO, ILO, & IDDC). I chose to address this gap and contribute to defining best evaluative practices in CBR.

Two years later, in 2012, the World Health Organization (WHO) created an international committee on CBR program evaluation and invited me to join. We have had two meetings so far: one was held in Agra, India (2012), and a second one was convened in London, United Kingdom (2014). I presented preliminary findings of my work in both of these and contributed to discussions on how to move CBR program evaluation forward. In addition to being a very relevant experience of international collaboration, this has enabled me to network with experts with similar interests from all over the world and has provided a platform to share the results of my doctoral research.

In this thesis, I advance knowledge regarding best practices in CBR program evaluation. I develop guidelines and a model grounded in a thorough literature review, lessons learned in the field and expert consensus. In the first chapter, I introduce the reader to the notion of CBR and to the evidence underlying its effectiveness. I then present my thesis statement and provide a methodological overview of the sequential three-step process in the following chapter. In Chapter 3, I review the body of knowledge on sound evaluative practices. This includes a systematic review on CBR program evaluation and an analysis of relevant program evaluation approaches. I then propose a model for CBR program evaluation based on the key features of the

sound evaluative practices identified. In the fourth chapter, I share the results of a field study conducted in South Africa about evaluative practices in CBR. More specifically, I designed an evaluation process from the best practices previously identified and I reflect on this experience to learn about applicable evaluation strategies. Chapter 5 presents an experts consultation, which was conducted to generate consensus on best practices in CBR program evaluation. I integrate insights from the various phases in Chapter 6 as I present practice guidelines for CBR program evaluation along with a model to summarize and organize their key features.

Two points should be made regarding the thesis format. Firstly, short questions, as well as first-person possessives and pronouns such as ‘I’, ‘my’ ‘we’ and ‘our’, are used throughout the thesis to be congruent with the narrative style adopted in Participatory Action Research (Herr & Anderson, 2005; McNiff & Whitehead, 2009). This enables me to tell the story of my learning journey as I reflect on the research process and findings, and to adjust my perspective. Secondly, I chose to write my thesis as a series of three articles published in scientific journals. I am the first author of all three since I designed the studies, conducted the data collection and analyses, and wrote the manuscripts.

The first article consists of a systematic review on best practices in CBR program evaluation. It is published in *Disability and Rehabilitation* and co-authored by my supervisors Dr. Michèle Hébert and Dr. Rachel Thibeault. Their role was to answer my questions and provide suggestions after reviewing my search strategy, my data analysis plan, and the article itself. The second article is a field study conducted in South Africa and published in *Disability, CBR and Inclusive Development*. This one is co-authored by my supervisors and a representative from the local NGO. I designed the study, shared the leadership with Rachel Thibeault during data collection, and wrote the evaluation report as well as the first draft of the manuscript. My

supervisors provided advice on the study design, reviewed my plans, and gave suggestions to enhance the clarity and choose the appropriate style for the evaluation report and the article. Annie Templeton, from *Goedgedacht* in South Africa, provided suggestions to address cultural and organizational issues, validated the analyses, and revised the article. The third article included in this thesis consists of a Delphi study on best practices for CBR program evaluation. It is published in *Disability & Rehabilitation*. Dr. Michèle Hébert, Dr. Rachel Thibeault and Dr. Debra Cameron co-authored this paper since they provided significant input in the choice of design, and reviewed the questionnaires, invitations, analyses, and final article. The publishers' permissions to include the articles in my thesis can be found in Appendix A.

As part of my degree requirements, I had to defend my proposal and submit my project to the Office of Research Ethics and Integrity of the University of Ottawa before data collection. I prepared all the documents, including the application form and appendices, and sent them to my supervisors for comments. I then revised the documents and sent them to my thesis committee members, Dr. Stéphane Poitras and Dr. Debra Cameron, for further comments. The file was sent to the Health Sciences and Science Research Ethics Board and ethical approval was granted in December 2011 (#H10-11-06, Appendix B). Managers from the South African NGO were invited to review the data collection plan to ensure that the project was beneficial to the local community without putting unnecessary burden on any group. They also provided suggestions for the study to remain aligned with local culture and organizational philosophy. The program evaluation report was only shared with the local NGO, for the sake of program improvement and accountability. The NGO is not associated with any ethics board and the study consisted of a reflection on lessons we had learned. Hence, no further ethical approval was required.

Acknowledgements

Four and a half years, a wedding, a child, and a baby on the way later, I feel that I have progressed enormously as a person and as a researcher in this doctoral adventure. I am no longer afraid of working on my own: I now have the confidence and skills to design, conduct and disseminate the findings of research projects independently. I now know how to develop projects that will not only advance knowledge, but will also be meaningful and useful to local communities. I have obviously learned a lot about community-based rehabilitation, program evaluation, and practice guidelines, and I have built a significant network with people and organizations involved in CBR at different levels. For all these reasons, I wish to highlight the contributions of all those who have made this doctoral thesis possible, enriching, and enjoyable.

Firstly, I would like to thank my supervisors, Professors Rachel Thibeault and Michèle Hébert, for your expertise, support, encouragements and generosity. More specifically, thank you Rachel for sharing your passion, rich field experience and zen attitude. Thank you Michèle for your rigour, rapidity and wisdom throughout the whole process. I also wish to thank Professors Debra Cameron and Stéphane Poitras, for being part of my thesis committee and sharing brilliant ideas. Thanks to all of you for making this learning journey extremely stimulating.

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Bursary. I was privileged to access so much learning and networking opportunities. Thank you to the Institute of Global Health of the University College London (UCL) for welcoming and challenging me during my research placement in 2014. Sincere thanks to Mary Wickenden, Senior Research Fellow, for making this possible and for sharing your experiences with me.

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Finally, thanks to all my friends and my family for encouraging me in this academic adventure. Thanks to my husband Nicholas for your support through all the ups and the small downs of this long journey. Thanks to my daughter Charlotte for being such a happy being: it has helped me tremendously as I have learnt to be more productive to spend more time with you!

Chapter 1: An Introduction to Community-Based Rehabilitation

This first chapter presents the background information necessary to understanding the context and the importance of this doctoral thesis. It first offers an overview of the situation of people with disabilities to highlight the necessity to include them in development initiatives. An overview of community-based rehabilitation (CBR), an inclusive community development strategy with a focus on the population living with a disability, follows. Finally, the evidence for the effectiveness of CBR is reviewed at the end of this introductory chapter.

1.1 The Issue of Disability: Why Does it Matter?

People with disabilities are the largest minority group on Earth: they represent approximately 15% of the world's population, or over one billion people (World Health Organization [WHO] & World Bank [WB], 2011). They face numerous barriers to active participation in their communities and cumulate disadvantages throughout their lives, as they are less likely to access early childhood care and education, primary, secondary and higher education, vocational training, employment, recreational activities, and health services (Harrison, 2005; WHO, United Nations Educational Scientific and Cultural Organization [UNESCO], International Labour Organization [ILO], & International Disability Development Consortium [IDDC], 2010; WHO & WB, 2011). As a consequence, they are more likely to be poor and vulnerable to a range of physical and mental health problems (Coleridge, 2006; WHO & WB, 2011). It is estimated that 80% of this population live in low- and middle-income countries, and they have yet to benefit significantly from global health and development initiatives (Coleridge, 2006, United Nations, 2011). Even the *Millennium Development Goals* (MDGs) made no explicit mention of disability in any of the eight goals and associated target indicators (United Nations, n.d.). A recent United Nations (UN) report on the inclusion of disability in MDGs

processes and strategies (2011) acknowledges this major oversight: many of the goals are unlikely to be met partly because initiatives have failed to reach a large number of individuals living with disabilities.

The UN *Convention of the Rights of Persons with Disabilities* (CRPD) (2008) has brought political attention to disability issues and will hopefully act as a catalyst in meeting the rights and needs of people with disabilities (Lang, 2009). This thesis focuses on one strategy aimed at reducing the rampant inequalities and at empowering people with disabilities: CBR.

1.2 CBR: Its Beginnings, Current Definition and Core Principles

Following the Alma Ata conference of 1978 on primary health care, WHO launched CBR to increase access to health care and rehabilitation for persons with disabilities in resource-poor areas. As it evolved, WHO joined forces with other organizations and moved beyond the provision of medical and rehabilitation services to consider issues of poverty, work, education and social participation. In 1994, the organizations produced a *Joint Position Paper on CBR* reflecting their common approach, a paper they updated in 2004 (ILO, UNESCO, & WHO, 2004a). They defined CBR as:

a strategy within general community development for the rehabilitation, equalization of opportunities, [poverty reduction,] and social inclusion of people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services. (ILO, UNESCO, & WHO, 2004a, p.2)

This document emphasizes that CBR programs should work with stakeholders from multiple sectors and make efforts to be inclusive of people of all age groups, types of disabilities,

genders and socioeconomic status. The 2010 *CBR Guidelines* (WHO, UNESCO, ILO, & IDDC) further clarify the concept of CBR and provide directions for implementation. They stress that CBR should foster inclusive community development through a twin-track, bottom-up approach: 1) ensuring that individuals with disabilities access mainstream development initiatives, and 2) providing community-based services that target the specific needs of those with disabilities when necessary. To do so, the guidelines clearly state that CBR programs must collaborate with existing health-sector services and government representatives (WHO, UNESCO, ILO, & IDDC). This may include, for example, advocating for greater physical access, training health workers on the needs of people with disabilities, organizing transport to facilities, or referring to services. To meet the specific needs of people with disabilities, CBR programs may, for example, provide basic assistive devices produced and maintained locally, or hold health promotion workshops in accessible formats (e.g. sign language).

The key features of CBR are articulated into a set of core principles in the *CBR Guidelines* (WHO, UNESCO, ILO, & IDDC, 2010). These are largely based on the UN *CRPD* (2008) and essential to grasp CBR's philosophy. Since they are derived from *CRPD* excerpts, the principles described in the guidelines are rather long and hard to remember. I chose to simplify them by regrouping them into five main themes: autonomy, inclusion, participation, empowerment and sustainability. Furthermore, because of the importance given to multisectoral collaboration in the *CBR Guidelines*, I added it as a sixth theme to guide CBR practice. The CBR Principles and associated themes are presented in Table 1.1.

Table 1.1

Main Themes Represented in the Core Principles Guiding CBR

Principles	Themes
Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons	Autonomy
Non-discrimination	Inclusion
Full and effective participation and inclusion in society	Participation and inclusion
Respect for differences and acceptance of persons with disabilities as part of human diversity and humanity	Inclusion
Equality of opportunity	Participation
Accessibility	Participation
Equality between men and women	Inclusion
Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.	Autonomy
Empowerment	Empowerment
Sustainability	Sustainability
	Multisectoral collaboration

Note. Principles from WHO, UNESCO, ILO, & IDDC (2010, p.25)

1.3 Emergence of a Conceptual Model: The CBR Matrix

Following an international consultation in 2003, the CBR Matrix emerged as a conceptual model guiding CBR implementation (ILO, UNESCO, & WHO, 2004b) (Figure 1.1). The matrix has five components: four development sectors (health, education, livelihood and social) and one crosscutting issue (empowerment). Each component is constituted of five elements, or development areas. CBR programs are not expected to tackle all development sectors: they should solely implement those interventions relevant to their needs and resources.

On the one hand, the development sectors targeted by CBR match the most common disadvantages faced by people with disabilities, thus giving CBR the potential to alleviate health, education, livelihood and social inequalities between people with and without disabilities. Since the *CBR Guidelines* are closely aligned with the CBR Matrix, with objectives, potential

activities, real-life examples and desirable outcomes provided for all of its components and elements, CBR programs implemented using the guidelines are likely to reflect CBR multidimensional and multisectoral nature.

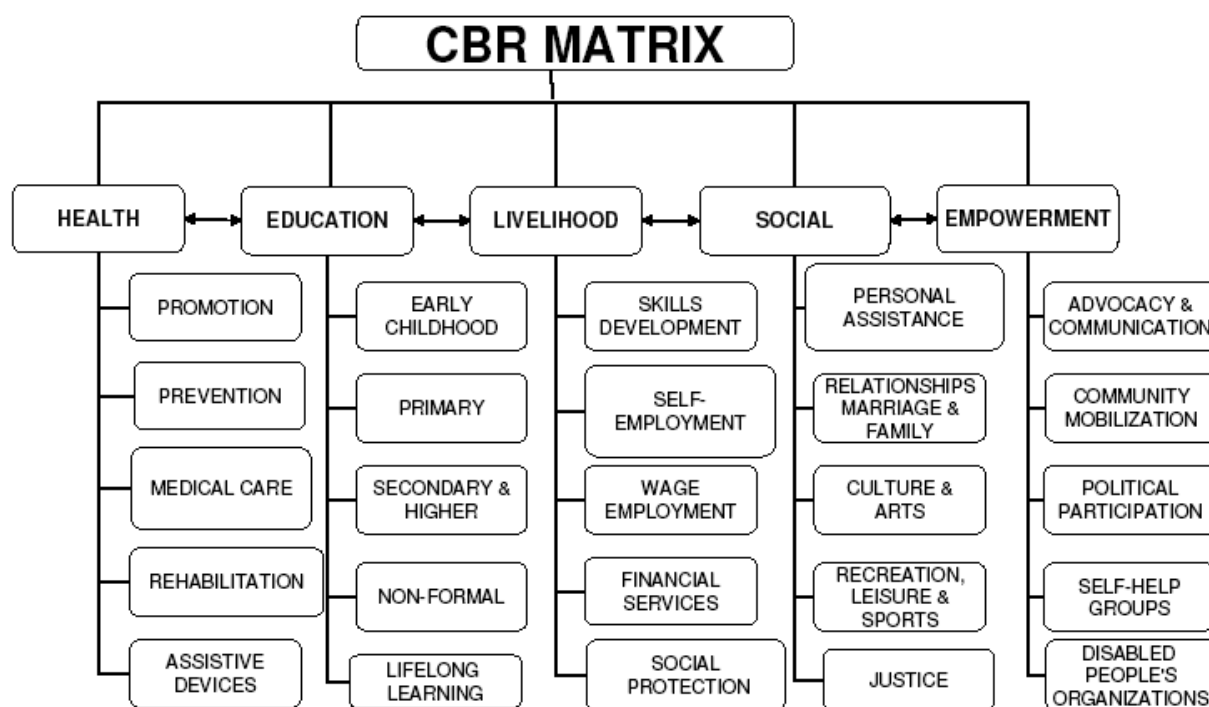


Figure 1.1. The CBR Matrix (ILO, UNESCO, & WHO, 2004b)

On the other hand, the fact that the visual representation of CBR is broad and centered around development sectors instead of core principles may be misleading as to what CBR really is. It may imply that any program delivering community services to people with disabilities, in one or more of the CBR Matrix cells, can call itself CBR. In addition, rehabilitation services provided in the community by health professionals are often referred to as community-based rehabilitation in the literature. Consequently, the term CBR found in publications' titles or keywords cannot guaranty that the programs described truly follow CBR core principles or its bottom-up, twin-track approach to inclusive community development. This is crucial because

CBR is not merely rehabilitation in the community, it is a multidimensional strategy implemented by and for people with disabilities (ILO, UNESCO, & WHO, 2004a).

1.4 Effectiveness of CBR: Is it Working and Under Which Conditions?

More than 35 years after its initial launch, with programs implemented in more than 90 countries, the evidence for CBR must be carefully examined. Finkenflugel, Wolffers and Huisjman (2005) conducted a review on the effectiveness of CBR for the 1978 to 2002 period. They searched five rehabilitation databases, reviewed the reference lists of included articles, and used names and biographies of leading authors to identify other articles. Their review focused on CBR in low- and middle-income countries and only included articles in English. To ensure the articles included were of good quality, they then excluded all those published in journals not indexed by PubMed, Social Sciences Citation Index, or Index Medicus. The authors did not assess the quality of the articles, nor did they verify if those included truly evaluated CBR programs. As some confusion between CBR and rehabilitation in the community exists in the literature, this extra step could have strengthened their review. The authors retrieved many theoretical papers and descriptive studies of implementation, but few program evaluations documenting both implementation and outcomes. They highlighted that study designs using control groups or pre and post evaluations are rare in CBR, with descriptive qualitative studies being much more frequent. While the latter can contribute significantly to the advancement of knowledge on CBR, the wide range of outcome measures chosen in the different studies represents an important challenge when one attempts to combine findings to draw conclusions about CBR effectiveness. The authors concluded that the evidence on CBR effectiveness and on the conditions under which these programs are most effective remains fragmented and largely insufficient (Finkenflugel et al., 2005). Nonetheless, the comprehensiveness of their review can be questioned as the exclusion of journals not indexed in specific databases led to the rejection of

publications from the *Asia Pacific Rehabilitation Journal*, which was a popular platform for studies from low- and middle-income countries at the time. Furthermore, the way the authors presented their findings makes it difficult to establish what evidence is available: they focused on the types of study conducted and the topics covered, but did not mention study results as to whether CBR is effective and, if so, under which conditions.

Velema, Ebenso and Fuzikawa (2008) further looked into the evidence available for CBR effectiveness. The title of their article, *Evidence for the effectiveness of rehabilitation-in-the-community programs*, is misleading and may lead to exclusion from CBR reviews. Because the authors specifically mentioned that they refer to CBR programs and because the articles included reflect this, their review is discussed here. The authors chose not to conduct a systematic search. In order to identify articles, they used those included in previous reviews on CBR and papers published in a special issue of the journal *Leprosy Review* on socioeconomic interventions, they performed a PubMed search, they reviewed the reference lists of the included articles, and they used personal contacts. The authors briefly commented on the quality of the included articles when reporting their results although no systematic quality assessment was conducted. Their analyses of the included studies from 1987 to 2007 indicate that: 1) educational interventions have enabled approximately 50% of children with disabilities to attend school in areas where CBR programs are in place, 2) economic interventions have increased the income of people with disabilities and improved their self-esteem and social status, 3) home-based training of disabled individuals and family members by CBR volunteers have led to better autonomy in daily activities for at least 50% of beneficiaries, and 4) CBR has contributed to improving community attitudes about people with disabilities (Velema et al., 2008). These results can be regarded as positive as they provide support for the effectiveness of CBR in relation to education, livelihood,

functional autonomy and social participation. Yet, they do not offer a comprehensive overview of the evidence available since only outcomes of very specific types of CBR interventions are available and since the search strategy was not systematic. Furthermore, because no baseline or control group is available for most of the included studies, with the exception of those relating to socioeconomic interventions, their conclusion regarding a 50% increase in school attendance following CBR appears insufficiently supported. This may not be solely attributable to CBR interventions as no baseline were provided regarding how many went to school before CBR programs were established, no comparisons with areas where no CBR programs operate were made, and no analyses of other interventions that might have been in place in those communities were done. Regarding economic interventions and home-based training, more nuances could be brought to their conclusions since some studies reported less substantial improvements, while others were not very rigorous. Nonetheless, their conclusion on community attitudes are well grounded in evidence: this includes perceptions of CBR workers and beneficiaries from different regions, analyses of participation of people with disabilities in community activities, and analyses of resources mobilized to improve the situation of disabled community members.

Cleaver and Nixon (2014) conducted a rigorous scoping review of the CBR literature encompassing low- and middle-income countries for the period immediately following Finkenflugel et al. (2005) time frame. Their aim was to investigate whether CBR research had followed the conceptual shift toward empowerment, participation and ownership by people with disabilities and other key stakeholders from low- and middle-income countries. They included 114 articles published in English in peer-reviewed journals from 2003 to 2012: 46% of those were empirical research and 28% were published in the *Asia Pacific Disability and Rehabilitation Journal*. The authors looked at who had contributed to the literature and

highlighted that 76% reported first author affiliations in universities or hospitals and 63% declared first author affiliations in high-income countries. They concluded that the voices of people with disabilities in low- and middle-income countries were poorly represented, and thus that the CBR literature did not follow the conceptual shift described. However, they did not analyze how the content of the articles contributes to the evidence for CBR, nor how it relates to the importance of empowerment, participation and ownership.

Another review by Robertson Emerson, Hatton and Yasamy (2012) summarized the evidence on the effectiveness of CBR for children with intellectual disabilities. A comprehensive search for articles was conducted: the main rehabilitation databases were used and organizations in low- and middle-income countries were contacted to identify other reports. The articles selection followed a systematic process. Nonetheless, the authors' choice to include studies that did not solely focus on children, and that included children with cerebral palsy, means that the evidence available might be overestimated and is more difficult to interpret. No clear assessment of methodological quality was conducted, but key elements of study designs are available for the 13 articles included to enable readers to make their own judgments. The authors concluded that the evidence is very low since few studies have focused on the effectiveness of CBR, and because the samples were highly heterogeneous in many studies. Positive changes for children with intellectual disabilities have been reported in motor and daily living skills, in parental attitudes and in community understanding. While some children appeared to have benefited from CBR interventions, others showed little or no progress. The authors acknowledged that their findings do not imply that CBR is ineffective, but rather suggested that investments in evaluation are needed to improve the evidence base.

A large study on the impact of CBR for people with different types of disabilities was published after the above-mentioned reviews (Deepak, Biggeri, Mauro, Kumar, & Griffo, 2013). It investigated the impact of CBR activities implemented through the collaboration of two NGOs in nine sub-districts in India. The evaluated program mostly uses mainstreaming as an inclusive community development strategy: CBR workers enable people with disabilities to access existing services. Household surveys were conducted with 1919 CBR beneficiaries and 455 people with disabilities from a control area. Key indicators were identified through a participatory exercise with CBR stakeholders and Disabled People's Organizations (DPOs) representatives. Their findings suggest that this cross-disability CBR program has had a positive impact on the health, education, livelihood, social participation and empowerment of people with disabilities. Those who appear to have benefited the most are people with physical disabilities: a significant positive difference was noted on 10 out of 14 variables across all five CBR components (health, education, livelihood, social participation and empowerment). Those whose improvements were less substantial were those with intellectual disabilities: a significant positive impact was noted on only 5 out of 14 variables associated with health, livelihood, social participation and empowerment, and no difference was found in access to and years of education. The results also showed a positive impact of CBR for individuals with visual disabilities on 7 out of 14 variables across four CBR components. For this group, no significant difference was found in relation to health outcomes. As for people with hearing and speech difficulties, the results indicated a positive impact on 7 out of 14 variables and across all CBR components. After an exhaustive review, this is the first study that squarely situates findings within the CBR Matrix and provides clear disaggregated data on the impact of CBR for individuals with different impairments.

1.5 Conclusion

In this first chapter, CBR was introduced as a potential strategy to equalize the opportunities for people with disabilities to become active members of their communities. The literature on CBR effectiveness was also reviewed. On the one hand, the literature consulted indicates that CBR programs, whether they use mainstreaming or direct service provision as their primary strategy, can have a positive impact on the lives of people with disabilities, their families and their communities (Deepak et al., 2013; Robertson et al., 2012; Velema et al., 2008). On the other hand, the reviews consulted have several limitations: two used questionable search strategies (Finkenflugel et al., 2005; Velema et al., 2008), none clearly appraised the scientific quality of the included studies (Cleaver & Nixon, 2014, Finkenflugel et al., 2015, Velema et al., 2008; Robertson et al., 2012), two did not analyze how the content of the included studies contributed to the knowledge base on CBR effectiveness (Cleaver & Nixon, 2014; Finkenflugel et al., 2005), and one included studies covering a broad range of ages and disabilities in a review meant to focus on children with intellectual disabilities (Robertson et al., 2012). As noted by Finkenflugel et al. (2005), few published studies have clearly described program activities and the context in which the outcomes described had been achieved. Furthermore, the wide range of outcome measures used makes it challenging to combine findings from different studies, as results are not situated within a common framework. Thus, I conclude that the evidence for CBR effectiveness and for the conditions under which CBR is most effective is promising, but remains largely fragmented, insufficient, and in need of more rigorous standards. To strengthen CBR's evidence base, I believe more rigorous studies and evaluations aligned with CBR values of inclusion, participation and empowerment are needed, along with greater coherence across the different contributions. In the next chapter, I demonstrate the need to identify key elements of sound CBR evaluation and present my research questions and objectives.

Chapter 2: Thesis Statement: How Should CBR Programs be Evaluated?

Chapter 2 first highlights the knowledge gap concerning the best ways to evaluate community-based rehabilitation (CBR) programs is presented. I then state my research questions and objectives, and define key concepts. Because this thesis is written as a series of articles, a methodology overview is introduced here and the reader is referred to subsequent chapters for further details specific to the systematic review (Chapter 3), the field study (Chapter 4) or the experts consultation (Chapter 5). The rationale for the study design is offered here along with the underlying paradigm. Ethical considerations follow at the end of this chapter.

2.1 Knowledge Gap: The Scarcity of Guidelines for CBR Program Evaluation

As others have suggested (Boyce & Ballantyne, 2000; Robertson et al., 2012), I also think that better evaluative systems are needed to scale up CBR. I believe that one of the most important reasons for the scarcity of evidence for CBR effectiveness is that very little guidance is available to those who wish to evaluate these programs. The *CBR Guidelines* (WHO, UNESCO, ILO, & IDDC, 2010) stress the need for CBR programs to be evaluated and suggest that the multisectoral nature of the strategy poses challenges to evaluators. Yet, this guide only provides very general information as to what could be evaluated and how. A guide to CBR monitoring and self-evaluation, published in 1996 (WHO & International Disability Consortium [IDC]), offers some direction on the selection of evaluation methods and on the translation of evaluation findings into action. Yet, it is not exhaustive and appears to be based on the opinion of a small number of experts involved in editing the guide. Evaluating CBR programs rigourously while remaining aligned with CBR values and giving a real voice to people with disabilities is challenging: evaluators need to deal with limited resources, with the multisectoral nature of this strategy, with diverse cultural and linguistic contexts, with large variations between programs, and with very limited monitoring systems.

Almost 20 years after the publication of the guide to CBR monitoring and self-evaluation (WHO & IDC, 1996), creating sound guidelines becomes paramount. I argue that guidelines for CBR program evaluation are needed to: 1) improve evaluative practices in CBR, 2) document the impact of CBR and the conditions under which these programs are most effective, 3) assist programs in being accountable to their communities and funders, and 4) inform decision-making about CBR programs. This can in turn scale up CBR programs and facilitate their implementation on a larger scale, thus meeting the needs of a broader proportion of people with disabilities from resource poor areas. To develop guidelines for CBR program evaluation, I strongly believe that one must first determine, through a comprehensive and rigorous process, what should be considered best practices in this field.

2.2 Research Questions

This thesis examined the following question: ***How should CBR program evaluations be conducted?*** More precisely, this study concentrated on what best practices in CBR program evaluation are in relation to the evaluation process, the framework that could be used and the data collection methods. Hence, the sub-questions are:

1. *What are the key features of a sound CBR program evaluation process?*
2. *What are the crucial steps included in a sound CBR program evaluation?*
3. *Should CBR program evaluations be situated within a specific framework?*
 - a. *If so, which one?*
 - b. *How should this framework be used?*
4. *What are the characteristics of suitable data collection methods for CBR program evaluation?*

2.3 Objective: To Define Best Practices in CBR Program Evaluation

The main objective of this thesis was to develop a model and a substantive theory on what should be considered best practices in CBR program evaluation, or critical features of sound evaluation. I wish to develop guidelines on how to conduct CBR program evaluations that: 1) are compatible with CBR core principles, including participation and empowerment of the most disadvantaged, 2) can be implemented in resource poor areas in a range of cultural contexts, 3) respect key features of sound program evaluations, 4) contribute to building the evidence base for CBR effectiveness, and most importantly, 5) are useful to local communities. To achieve this, three sub-objectives were proposed: 1) to review the literature on CBR program evaluation, 2) to draw lessons from a CBR program evaluation in South Africa, and 3) to generate expert consensus.

2.4 Definition of Key Concepts

This dissertation's key concepts are defined in Table 2.1 to ensure that the questions and objectives described above are clear to the reader.

Table 2.1

Definition of Key Concepts

Concepts	Definitions
Disability	According to the <i>International Classification of Functioning, Disability and Health</i> (ICF), disability is a broad term that encompasses three levels: impairments in body functions or structures, activity limitations, and participation restrictions in life situations (WHO, 2002). This definition stands at mid-point between the medical model of disability, where the onus lies squarely with the individual with a disability, and the social model of disability, where social barriers are seen as the sole source of disabilities. In this thesis, disability is considered to be the result of the interaction between health conditions, such as injuries, disorders, or diseases, and contextual factors associated with the person and the environment in which he or she lives.
Community-based rehabilitation	The term community-based rehabilitation (CBR) is often used very broadly to refer to rehabilitation occurring in the community. This thesis concentrates on CBR as an inclusive community development strategy for the rehabilitation, social inclusion, poverty reduction and equalization of opportunities of people with disabilities (ILO, UNESCO & WHO, 2004a).

Program evaluation	Program evaluation is a systematic investigation of a program's value using scientifically valid and socially relevant methods; it primarily serves the program at stake (Brousselle, Champagne, Contandriopoulos, & Hartz, 2009). Evaluative research assesses a program's value added, and how and why changes are observed; it contributes to the advancement of knowledge in a given area. In order to gain the most from the literature available, insights are drawn from both fields even though the focus is on program evaluation.
Program evaluation theory	A program evaluation theory is a set of propositions on program evaluation opened to peer critique (Stufflebeam & Coryn, 2014). My theory on best practices in CBR program evaluation is therefore a set of propositions about best practices in this field.
Framework	The terms frameworks and models are often used interchangeably. In this thesis, a framework consists of an illustration and description of the main variables relevant to a given topic and provides a unified and standard language in a discipline (Hagedorn, Arzt, & Peters, 2002, WHO, 2002). The ICF is one example of a framework used across the world to study health and rehabilitation. Results of different studies are more easily compared when situated within a common framework. A CBR evaluation framework is a visual representation of the core elements to be evaluated in CBR.
Practice guidelines	Practice guidelines are "systematically developed statements to assist (...) decisions" (Agree Next Step Consortium, 2009, p.1). In the context of program evaluation, those can be seen as standards to guide and stimulate reflective evaluative practice (Yarbrough, Shula, Hopson, & Caruthers, 2011). They are solid recommendations for practice and may be accompanied by suggestions for implementation. I will sometimes refer to those as best practice guidelines to acknowledge that the recommendations emerging from this study will be systematically developed from the literature, validated and refined through field experience, and will also represent the consensus of a group of experts. This does not mean that other methods might not be appropriate, but rather that the evaluator can trust that the recommendations correspond to best practices. People conducting evaluations will always need to judge whether the recommendations can apply to their context.
Practice model	Practice models include recommendations grounded in theory that can support clinical reasoning associated with a specific problem (Direttte, 2013). Here, the practice model for CBR evaluation consists of a visual representation of the core features of best evaluative practices in CBR. It is grounded in the guidelines and substantial theory generated.

2.5 Methodological Overview

In this section, I present an overview of the methodology used to develop my model and theory on best practices in CBR program evaluation and explain my methodological decisions.

2.5.1 Background: How are guidelines developed and what influenced my choices?

Most often, practice guidelines are developed once a systematic review of the evidence available has been conducted (AGREE Next Step Consortium, 2009; Bowker, Lachanpaul, Atkinson, Armon, MacFaul, et al., 2008). Nonetheless, reviewing the literature is not always sufficient, especially when the topic of interest is methodology. Bowker and colleagues (2008) recommend that a formal consultation process be launched when insufficient directions are provided in the literature. They also indicate that external evaluation and field-testing should be performed. Essential features of the development of high quality practice guidelines include rigour, use of evidence-based information, transparency and stakeholder involvement (AGREE Next Step Consortium, 2009; Bowker et al., 2008). In the context of program evaluation, guidelines are standards or recommendations to guide decisions about how to conduct an evaluation. An excellent example is the Program Evaluation Standards, which consist of 30 statements about sound evaluations (Yarbrough et al., 2011). Those were developed through extensive experts consultation, review of the literature, and field trials.

In order to remain congruent with the CBR philosophy, I wanted to develop a methodology that would also value participation and empowerment of local communities (WHO, UNESCO, ILO, & IDDC, 2010). I approached the situation from a pragmatic paradigm in which the strengths of qualitative and quantitative methods are combined to obtain a holistic understanding (Freshwater & Cahill, 2007; Onwuegbuzie, 2000). Pragmatists advocate for an epistemological continuum, believe in the existence of both subjective and objective reality and in the unification of positivism, interpretivism and postmodernism. Furthermore, I took a Participatory Action Research (PAR) perspective to this iterative learning journey as I valued both scientific and experiential knowledge and aimed to produce knowledge that would be

deemed valuable to the scientific community and useful to CBR stakeholders (Herr & Anderson, 2005; Kindon, Pain, & Kesby, 2007).

2.5.2 A sequential three-step process to develop guidelines for CBR program

evaluation. I used a three-step sequential mixed methods design to develop best practice statements that are congruent with the core principles of CBR, my pragmatic and PAR lenses, and recommendations for guidelines development. The three phases of this study are a review of the literature, a field study and an experts consultation. Although desirable, it is beyond this thesis' scope to add exhaustive field-testing and external appraisal. A grounded theory approach was used to analyze the insights from each study phase and bring them together into a comprehensive and coherent whole (Creswell, 2013). I went back and forth between data collection and analysis, and developing the theory, as I used constant comparative analysis to add lessons learned in each phase to the evolving theory. After each phase, questions guiding my analyses included: Does this represent a new theme? Can this segment be coded into an existing theme? Should the initial themes developed be modified or combined? Are some themes particularly critical? Should some themes be deleted? Does this new segment represent a critical feature of sound program evaluation, a suggestion on how to implement one of the guidelines, a nuance that should be brought to a guideline, or a confirmation of the importance of a guideline? Throughout the process, I aimed to develop a solid, clear and manageable theory on best practices in CBR program evaluation.

2.5.2.1 Using the literature as a starting point. The first step of this study consisted of a literature review, including a systematic review of articles and guidelines on how CBR program evaluation should be conducted and a review of key textbooks on program evaluation. The former was done to identify what is usually considered best practices in CBR program

evaluation, as well as areas of disagreement in the literature. The process used to search the literature, select and evaluate articles, is described in details in Chapter 3, and was meant to identify suitable existing program evaluation approaches and key elements of sound evaluations. Inferences stemming from the literature review yielded an initial model for CBR program evaluations. This provided directions for the program evaluation conducted in Phase 2 and for the preparation of the questionnaire for the experts consultation in Phase 3. I used the literature as a starting point as I valued knowledge and opinions that others had shared, but moved beyond this to develop guidelines that can be readily implemented and represent expert consensus.

2.5.2.2 Learning from the field: A case study. To foster the guidelines' applicability, and in an attempt to give a voice to those most concerned, Phase 2 consisted of a field study in a rural area of South Africa (Chapter 4). A case study allows researchers to gain substantial understanding about complex real-life issues, and thus, is often a core component of sequential mixed methods designs (Creswell, 2013; Lalor, Casey, Elliot, Coyne, Comiskey, et al., 2013). More specifically, an evaluation of a CBR program providing services to vulnerable children was conducted. The non-governmental organization (NGO) had requested help to evaluate its processes and outcomes. The literature review conducted, as well as principles from empowerment evaluation (Fetterman & Wandersman, 2005) guided the program evaluation design. I took this opportunity to learn from this field experience as I reflected on the evaluation process and asked for feedback from all those involved. This follows my PAR lens, as I valued the reflections of all stakeholders on the research process, including my own perspective as a researcher (Herr & Anderson, 2005; Kindon, Pain, & Kesby, 2007). The methodology used for this field study can be found in Chapter 4. In order to be accountable to our partners and to promote change, an evaluation report was produced for the South African organization involved,

highlighting strengths and areas where changes may be considered. Furthermore, my supervisor (RT) continues to accompany the NGO in cycles of reflection and action congruent with PAR.

2.5.2.3 Generating expert consensus: A Delphi study. The third phase of this study was built upon the findings of the two previous ones. A Delphi study was conducted in order to reach consensus within a group of CBR experts on what should be considered best evaluative practices (Chapter 5). Delphi studies represent a formal consensus methodology and are appropriate to generate collective agreement with experts from a wide range of geographical areas (Bowker et al., 2008). In this study, participants were provided with a summary of the findings from the previous research phases and the questionnaire used was built using these insights. It contained questions on agreement with different propositions as well as open-ended questions to leave space for substantial input from panellists. To maximize acceptance of the best practice statements generated, and to remain true to the value of inclusion at the heart of CBR, efforts were made to include representatives from all groups involved in CBR. This includes people with disabilities, field managers, academics, as well as employees of national and international organizations from all continents. This is also congruent with PAR as contributions from panellists from different vantage points are treated equally; all are considered reflexive agents capable of contributing to collective learning and consensus building (Kindon et al., 2007).

2.6 Ethical Considerations

The research process closely followed the core principles of the *Tri-Council Policy Statement: Conduct of Research Involving Humans*, which are respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERCC], & Social Sciences and Humanities Research Council of Canada [SSHRC], 2010). Ethical approval was granted by the Research Ethics Board of the University of Ottawa before the beginning of the data collection (#H10-11-

06). The main considerations for each of the above-mentioned categories are summarized below, while the mechanics of methods are described in Chapters 3 and 4 (i.e. field study and experts consultation respectively).

2.6.1 Respect for persons. Individuals' autonomy was highly valued and respected. It is one of the most important principles leading ethical decisions (CIHR, NSERCC, & SSHRCC, 2010; Seedhouse, 2009). Firstly, free, informed and ongoing consent was documented in the field study and in the experts consultation. Secondly, participants were informed that they had the choice to participate or not and that there would be no negative consequences if they chose not to or if they withdrew their participation at any time. Furthermore, in congruence with Seedhouse's (2009) guidance on moral obligations, extra care was taken in our partnership with the South African NGO to remain transparent and only make promises that we could keep.

2.6.2 Concern for welfare. Welfare refers to the quality of life of persons or groups and encompasses both potential benefits and risks associated with their participation (CIHR, NSERCC, & SSHRCC, 2010). Except for the time devoted to contribute to the study, there were no negative consequences for the participants. In all cases, data was analyzed and reported as a group so that no individual could be identified. In the field study, groups were homogeneous in order for all to share their opinions freely, and participants agreed not to share what had been discussed outside the group. When sensitive matters were discussed, participants had the opportunity to express their ideas individually. This was particularly essential for staff members and parents of children attending the South African program. During the fieldwork, we used the term "disadvantaged children" instead of "children with foetal alcohol spectrum disorder" or "children with disabilities", to avoid labeling that was deemed detrimental by our local partners.

In addition, the field study was designed to be as useful as possible to our local partners: they have benefited from the thorough evaluation they had requested, and an empowerment approach was used to build local evaluation capacity. With regard to the experts consultation, no material incentives were provided. Nonetheless, it was agreed that their contribution would be acknowledged in the publication following this study. Since all panellists were involved in CBR, it is believed that they were motivated to advance knowledge and could potentially use the findings to guide their own work.

2.6.3 Justice. Justice in research is associated with treating people fairly and equally by sharing the burdens and benefits of a project (CIHR, NSERCC, & SSHRCC, 2010; Seedhouse, 2009). The individuals most affected by the South African program were invited to contribute to the field study, including parents, staff members and managers. The input of children was not sought at this point because the evaluation focused on children aged zero to six years of age. In the experts consultation, snowball sampling was used to identify potential participants working directly in CBR programs, including people with disabilities. Furthermore, I wanted to ensure that the knowledge generated would be accessible to all, regardless of their institutional affiliations. This is especially crucial in the context of CBR in order for program stakeholders and beneficiaries from resource-poor areas to benefit from the project. The first two articles are published in open-access journals. The last article will be freely available in my thesis shortly after its publication on the journal's website.

2.7 Conclusion

In this chapter, I stressed the need for well-developed guidelines on how to evaluate CBR programs. I presented my research questions regarding what should be considered sound evaluative practices in CBR in relation to the characteristics of the process, methods and frameworks. I also provided a methodological overview to clarify how the three phases build on

each other and enabled me to develop a model and a substantive theory on CBR program evaluation that are grounded in the literature available, the richness of a field experience, and experts consensus.

Chapter 3: Using the Literature as a Starting Point

To generate an initial model for best practices to evaluate community-based rehabilitation programs, a thorough literature review was conducted. The objective was to identify potential features of sound CBR program evaluation processes and methods, as well as guiding frameworks. A systematic search for articles and guidelines associated with CBR evaluation was performed in order to explore and establish what is usually considered sound evaluative practice in this field, as well as areas of disagreement between authors. This review is published in *Disability & Rehabilitation* (2014): ‘A systematic review on how to conduct evaluations in community-based rehabilitation’. The reader should note that conclusions at the end of the review are based on several criteria: types of articles, one or multiple documents recommending this feature, whether authors agreed or had divergent views, congruence with CBR values and evaluation standards (WHO, UNESCO, ILO, & IDDC, 2010), and results of scientific quality assessments facilitated by the use of standardized scales.

To ensure that the model generated would be congruent with sound evaluative practices, program evaluation theories were also examined to identify suitable approaches used in other fields and key features of sound program evaluations. Nine approaches were selected because they promoted inclusion, participation, empowerment and sustainability, or because they added complementary information to what was found specifically for CBR in the systematic review. Key events in my learning journey influenced the choice of evaluation approaches over others: these include reading Alkin’s (2003) book on evaluation roots, attending the American Evaluation Association’s Summer Institute in 2012 where I participated in workshops led by leaders of some evaluation theorists, being guided by my supervisors to become acquainted with some approaches, and being involved in a preliminary field visit in South Africa in 2011. Using

the main insights from this literature review, I developed an initial best practice model for CBR program evaluation. It is presented at the end of this chapter and integrates knowledge from the literature on CBR evaluation and from suitable program evaluation approaches.

3.1 A Systematic Review on How to Conduct Evaluations in Community-Based Rehabilitation – FIRST ARTICLE

Marie Grandisson, Michèle Hébert and Rachel Thibeault

School of Rehabilitation Sciences, University of Ottawa, Canada

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REVIEW

A systematic review on how to conduct evaluations in community-based rehabilitation

Marie Grandisson^{1,2}, Michèle Hébert¹, and Rachel Thibeault¹

¹School of Rehabilitation, Faculty of Health Sciences, University of Ottawa, Canada and ²Occupational Therapy Department, Université du Québec à Trois-Rivières, Canada

Abstract

Purpose: Community-based rehabilitation (CBR) must prove that it is making a significant difference for people with disabilities in low- and middle-income countries. Yet, evaluation is not a common practice and the evidence for its effectiveness is fragmented and largely insufficient. The objective of this article was to review the literature on best practices in program evaluation in CBR in relation to the evaluative process, the frameworks, and the methods of data collection. **Method:** A systematic search was conducted on five rehabilitation databases and the World Health Organization website with keywords associated with CBR and program evaluation. Two independent researchers selected the articles. **Results:** Twenty-two documents were included. The results suggest that (1) the evaluative process needs to be conducted in close collaboration with the local community, including people with disabilities, and to be followed by sharing the findings and taking actions, (2) many frameworks have been proposed to evaluate CBR but no agreement has been reached, and (3) qualitative methodologies have dominated the scene in CBR so far, but their combination with quantitative methods has a lot of potential to better capture the effectiveness of this strategy. **Conclusions:** In order to facilitate and improve evaluations in CBR, there is an urgent need to agree on a common framework, such as the CBR matrix, and to develop best practice guidelines based on the literature available and consensus among a group of experts. These will need to demonstrate a good balance between community development and standards for effective evaluations.

Keywords

Community-based rehabilitation, evaluation process, framework, methods of data collection, program evaluation

History

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► Implications for Rehabilitation

- In the quest for evidence of the effectiveness of community-based rehabilitation (CBR), a shared program evaluation framework would better enable the combination of findings from different studies.
- The evaluation of CBR programs should always include sharing findings and taking action for the sake of the local community.
- Although qualitative methodologies have dominated the scene in CBR and remain highly relevant, there is also a call for the inclusion of quantitative indicators in order to capture the progress made by people participating in CBR programs.
- The production of best practice guidelines for evaluation in CBR could foster accountable and empowering program evaluations that are congruent with the principles at the heart of CBR and the standards for effective evaluations.

Introduction

People with disabilities represent approximately 15% of the world's population and are among the poorest and most marginalized of many communities [1]. In 1978, in an attempt to decrease the burden of disability in low- and middle-income countries, the World Health Organization (WHO) launched a strategy called community-based rehabilitation (CBR) [2]. CBR is

now implemented in more than 90 countries and is defined as an inclusive community development strategy, which aims at the equalization of opportunities, rehabilitation, poverty reduction, and social inclusion of the population living with a disability [3]. It is critical to evaluate existing CBR programs and to demonstrate their effectiveness in order to promote their sustainability and ongoing financial support, as well as the development of new programs based on the lessons learned from more than 30 years of experience in CBR. Yet, program evaluation does not seem to be common practice in the field, nor always congruent with standards for effective evaluations.

A review on the effectiveness of CBR programs by Finkenflugel et al. [4] came to an unfortunate conclusion: evidence on the effectiveness and on the conditions under which CBR programs are

most effective remains fragmented and largely insufficient. These authors retrieved few program evaluations on the effectiveness of CBR documenting both implementation and outcomes and highlighted that rigorous controlled studies on the efficacy of CBR were extremely rare. In addition, the wide range of outcomes analyzed in the different studies make it almost impossible to get a good general idea of the efficacy and effectiveness of CBR. Ultimately, there is very little consensus on how program evaluation and evaluative research should be conducted in order to be as close as possible to scientific standards, while remaining in harmony with CBR philosophy and the context of its implementation in low- and middle-income countries.

As Boyce and Ballantyne [5], we believe that CBR will not survive unless better and more systematic program evaluation systems are used to document the outcomes and the effectiveness of this strategy. This systematic review aims to document: (1) the characteristics of the process that could be followed in the evaluation of CBR programs, (2) the way in which a framework or classification model could help frame the choice of outcome measures, and (3) the characteristics of the data collection methods that could be privileged. This study proposes a thorough look at the recommendations available in the literature and represents the first step in the preparation of best practice guidelines for program evaluation in CBR.

Method

Search strategy

A systematic search was conducted by the first author (MG) on the main rehabilitation databases (CINAHL, Embase, MEDLINE, PsychINFO, and Scopus) with the keywords “community-based rehabilitation” AND “program evaluation” (OR evaluative research OR process OR evidence OR evidence-based OR framework OR classification model OR conceptual model OR methods). Because of the confusion present in the literature between rehabilitation happening in the community and CBR as a community development strategy, no synonym was included for the first key word. The years 1994–2011 were searched as 1994 is the year when the first joint position statement on CBR was published [3]. Articles published in this period are considered more representative of CBR today. In addition, a manual search was done on the WHO website. Finally, the references of the included articles were reviewed.

Inclusion and exclusion criteria

The selection of the articles that could provide indication on the process, models, and methods to be privileged in CBR program evaluation was conducted by two researchers who looked at all titles and abstracts, and read the full articles when in doubt. Disagreements on inclusion were resolved through discussion. Inclusion criteria were: (1) talking about CBR, as defined in the joint position paper in 1994 or 2004 (i.e., community development strategy), (2) having evaluation as a major theme, more precisely how evaluations should be done, (3) published in English or French. Articles reporting program evaluations without explicitly reflecting on the methodologies used were excluded. Peer-reviewed articles and guidelines were included, but book chapters, articles in newsletters, and articles published in journals without archives were excluded. Consistent with the suggestions of Kuipers and Harknett [6] and Mitchell [7], both program evaluation and evaluative research were considered; program evaluations can contribute to the evidence base if process and outcomes are described together, and if the outcomes that stand out in varied contexts and programs are verified using analytic study designs.

Methodological quality assessment of the studies

In order to make judgment on whether the recommendations for program evaluation represent a high level of evidence, two researchers assessed the methodological quality of all included studies, using tools appropriate for each type of study. The CASP tool was used to evaluate the methodological quality of observational qualitative studies [8], the AMSTAR scale for systematic reviews [9], the STROBE statement checklist for observational quantitative studies [10], and the AGREE II instrument for practice guidelines [11]. No appraisal tool was used to assess the quality of editorials (experts' opinions) since these are generally considered to be the lowest possible level of evidence. The two researchers compared their assessment of the methodological quality of each article and reached consensus for the global rating of each article through discussion.

Both researchers also evaluated the strengths and weaknesses of each document in relation to the congruence with best practices in program evaluation and CBR. The four standards for effective evaluations from the Centre for Disease Control and Prevention (i.e., utility, feasibility, propriety, accuracy) were used as reference for best practices in program evaluation [12]. The principles of CBR applicable to program evaluation (i.e., inclusion, participation, empowerment) served as reference for the CBR philosophy [2].

Results

Articles and documents included

Some 373 articles were retrieved from the databases and 13 documents from the WHO website. In total, 22 documents met all inclusion criteria, two of which were found on the WHO website, and one was added after revision of the reference lists of the included articles (Figure 1). These included observational studies, practice guidelines, literature reviews and editorials. The characteristics of the included documents and the results of the quality assessments are provided in Appendix A. A list of the excluded articles is provided in Appendix B.

Characteristics of the program evaluation process

Table 1 provides a detailed description of the characteristics of the evaluation process found in the nine documents that provided specific suggestions on program evaluation processes that are most relevant in CBR. These were divided in three categories that emerged from the findings: people who should be involved in the evaluation process, steps to follow, and time when the evaluation should take place.

In relation to who should be involved in the evaluation, the findings of this literature review suggest that the participation of the local community, including people with disabilities, is critical to ensure local relevance [5,14]. They also propose that self-assessment and external evaluations are suitable options [2,17,18].

Concerning the steps to follow when conducting CBR program evaluation, the need to start by focusing the evaluation process came out [2,5,18]. Two guidelines suggested that relevance, efficiency, effectiveness, sustainability, and social impacts could be used to focus the evaluation question [2,18]. Another element recommended by many authors is the completion of the evaluation cycle with reporting the findings and taking actions to improve the program [2,5,7,14,17,18].

As for the time when it is most appropriate to conduct an evaluation, the findings indicate that evaluation should be part of the regular activities of CBR programs, from the planning phase up to the follow-up upon completion of the program [17,18]. Many authors highlighted that the lack of baseline data in many

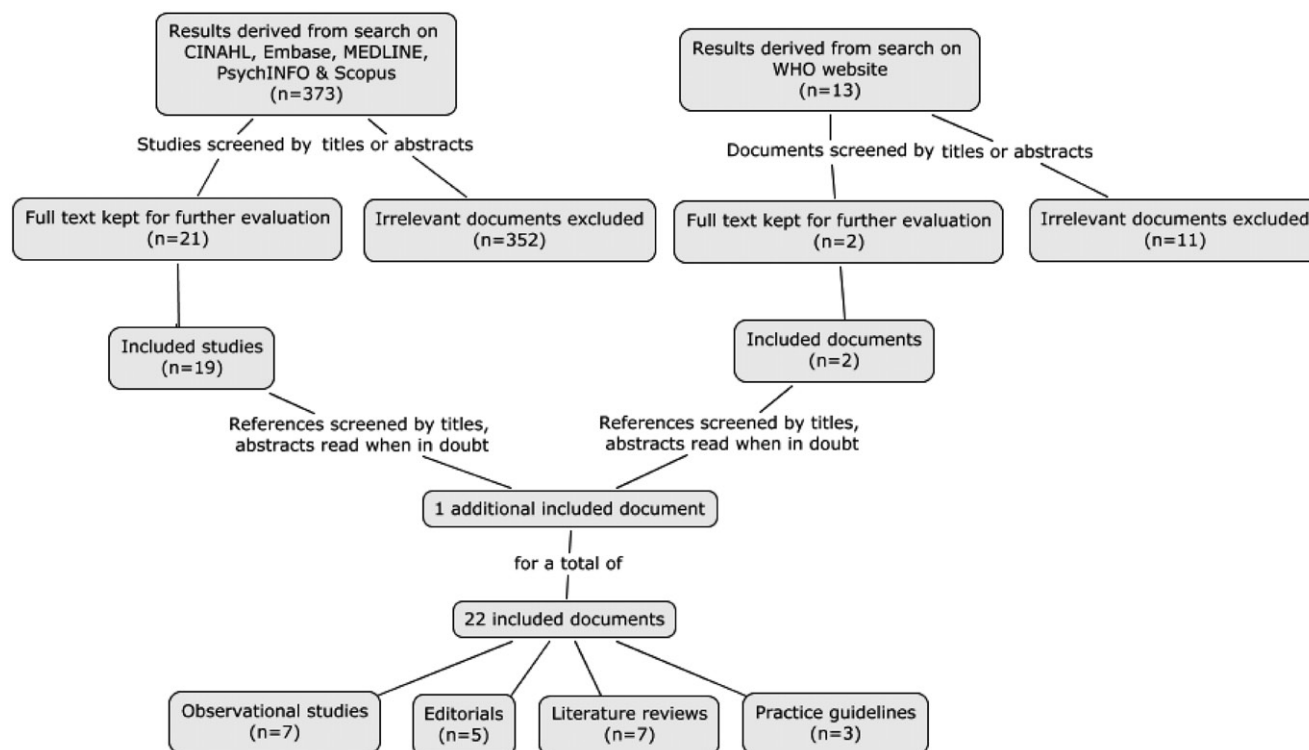


Figure 1. Flow chart for the selection of the articles.

CBR evaluations make it very challenging to capture the change happening over time [2,13,15,16].

Framework: process and outcomes used in program evaluation

A total of 13 classifications for CBR were identified in this review, including a broad variety of potential process and outcome measures, as well as indicators. They were not all presented as models for evaluation by the authors, but all included different categories on what should be measured when evaluating CBR programs. The different frameworks are presented in Table 2, along with process and outcome measures when available. The suggestions of the authors are divided in two categories: those associated with the implementation of the program and those associated with the outcomes of CBR.

Four articles suggest that CBR would certainly benefit from using outcomes and indicators derived from classification models [13,15,27,28]. Thomas [15] suggested that the desirable outcomes proposed in the CBR Guidelines for each element of the CBR matrix should be used to guide the choice of outcomes and indicators in CBR evaluations. Wirz and Thomas [27] believe that a bank of ready-to-use indicators derived from classification systems is needed while others argue that it is best to create a framework and indicators that meet the specific needs of the program to be evaluated [19,20].

Methods of data collection in program evaluation

Of the 22 documents, 15 had specific recommendations on the characteristics of the methods of data collection that are most relevant for CBR (see Table 3). Most authors agree that it is usually best to use more than one method to enable triangulation [2,6,18,20,22,26]. The findings highlight that traditional qualitative methodologies have been used extensively in CBR evaluations [29], but some authors argue that mixed methods and quantitative methodologies have more potential to contribute to demonstrating the effectiveness of CBR programs [13,18,27].

One point of disagreement in the literature lies in the need for tools that would be relevant in all contexts or some that would be context-specific.

Discussion

The review conducted provides insight into what should be considered best practices in CBR program evaluations. First, the need for the evaluative process to be focused on taking action in light of the results is certainly congruent with the utility and propriety standards for effective evaluations and the empowerment principle in CBR [2,7,14]. However, it appears that only Boyce and Ballantyne [5] have emphasized the need for the process itself to be empowering, so that the local community can become the leader of their evaluation. Based on our field experiences in CBR, we believe that CBR would gain from applying some of the principles proposed by Fetterman and Wandersman [31] to design and engage in empowering evaluations that would foster greater community ownership and sustainability.

Second, the lack of consensus on which classification model to use contributes to a very fragmented evidence-base for CBR, as there is no common language [4]. The authors of three articles suggest that CBR needs a common framework from which to derive outcomes for evaluations [15,27,28] while two other groups propose that a localized framework would be better suited to a bottom-up approach like CBR [19,20]. We propose that evaluators need to join forces towards a common framework enabling the combination of findings in the quest for evidence for CBR effectiveness, but that this framework must be clearly defined, comprehensive, and flexible to enable local adaptability. We agree with Thomas [15] that the CBR matrix could be an important piece of this framework since it was developed with the contributions of experts and managers of the field, and because each element is now explicitly described in the CBR Guidelines. The other frameworks available in the literature could help determine the most relevant evaluation questions while providing

Table 1. Findings about the characteristics of the evaluation process for CBR.

	Characteristics of the evaluation process		
	People who should be involved	Steps to follow	Time to evaluate
Boyce and Ballantyne [5]	People with disabilities and other key stakeholders in the community should be involved in all the steps. They should be empowered through coaching and training. Evaluations should be as participatory as possible.	Decide whether or not to evaluate, determine the objectives and indicators, select coordinators, choose methods, write the proposal, prepare and test the methods, collect the information, analyze the information, and report the results.	–
Cornielje et al. [13]	–	–	Importance of baseline survey (before implementation).
Mitchell [7]	–	The last step should be to draw attention to CBR by reporting the results publicly.	–
Price and Kuipers [14]	The participation of the community is essential to ensure local relevance.	The process should be iterative and involve cycles of action and reflection.	–
Thomas [15]	–	–	Importance of collecting baseline data (before implementation).
Velema et al. [16]	–	–	Importance of collecting baseline (before implementation) and follow-up data on people who completed the program.
WHO and IDC [17]	CBR programs should engage in self-reflection (self-assessment).	The last step should be to report findings and meet community members to make decisions to improve the program.	Incorporate monitoring and self-assessment in regular activities of CBR programs.
WHO et al. [2]	Both internal and external evaluations can be valuable, but a combination of both approaches would ideally be used.	1. Focus the evaluation (purpose and first questions) 2. Collect information (to answer the questions) 3. Analyze the information and draw conclusions (statistical calculations or thematic analyses) 4. Share findings and take action (write report, meet community members, influence decisions, act on the results)	Importance of collecting baseline data when implementing CBR programs. Specific points in time during the project cycle are relevant for evaluation (e.g., midway through the implementation, immediately after completion of the project, some time afterwards).
Zhao and Kwok [18]	There are many possibilities, including self-evaluation, mutual evaluation (exchange between two CBR programs), higher authorities evaluation, and external evaluation.	1. Make a detailed evaluation plan 2. Collect materials and conducting investigation 3. Analyze results 4. Make evaluation report and give suggestion 5. Feedback of results and integration into practice	At regular intervals, including baseline survey before implementation, periodical evaluation during implementation, eventual evaluation when the program ends, and follow-up evaluation some time after.

additional ideas for the process and outcome measures that can be appropriate for the particular context. Table 4 presents a proposition for a shared framework for program evaluation in CBR. It integrates the CBR matrix and the highlights from the other frameworks. It is structured in the respect of the hierarchy of evaluations [32] in order to facilitate the development of effective evaluations. The idea would be situate evaluations on both axes, the component and element of the CBR matrix evaluated, and the type(s) of question(s) studied (i.e., relevance, process, outcomes or cost). Further validation with experts and on the field is now needed.

Although qualitative methods have dominated the scene in CBR program evaluation for now, and remain highly relevant, the need to incorporate quantitative indicators to capture the progress made by people participating in CBR programs is identified explicitly in three articles [13,27] and is certainly congruent with a quest for greater accuracy in evaluations. The challenge is to determine how to do so without losing flexibility in evaluations, and without renouncing to the richness and power that qualitative

methodologies can have in engaging local communities. That being said, it is clear that the most important is for the methods to be suitable for the local community.

Most of the recommendations from the documents included in this review were highly congruent with the CBR principles of inclusion and participation, and the context of its implementation in resource-poor areas, but not always completely so with the empowerment principle and with the standards for effective evaluations and good research. This weakness, along with the lack of common language and framework in CBR before the publication of the CBR Guidelines, certainly has posed serious threats to the recognition and advancement of this strategy. Even though this review does not provide level 1 evidence for one type of evaluation over another, it certainly offers insights into what could be considered best practices in the field and highlights the need to move towards a culture of evaluation where reflection and action are incorporated in the regular activities of CBR programs. We believe that CBR now requires best practice guidelines for program evaluation, clarifying what is the

Table 2. Frameworks proposed in the CBR literature and their associated process and outcome measures.

PROCESS: Framework categories and measures	OUTCOMES: Framework categories and measures
<u>Adeoye et al. [19]</u> Implementation: role of people with disabilities, role of family, role of community, role of health services, role of educational services, role of vocational services, role of social services, challenges to implementation - Leadership role, formation of self-help groups, program coverage, participation in planning-implementing, access to health services, health education, home based care/intervention, access to educational services and equipments, inclusive education Policies, strategies, activities, and challenges to: community development, rehabilitation, equalization of opportunities, and social inclusion. - Policies: mainstreaming, participation, implementation of laws and guidelines, implementation of disability policy - Strategies: participation in planning-implementation, promoting community awareness, changing community attitudes, sign language training, promoting/advocating, increasing program coverage - Activities: income-generating activities, sustainability, collecting baseline data, technical aids and services, participation in community, participation in family, employment of people with disabilities, personal development and skills, access to justice, access to employment, social integration, inclusive education, leadership role of people with disabilities - Challenges: sustainability, unemployment, inadequate equipments, non-implementation of disability policies, inadequate access to CBR officials, communication barrier, discrimination, sexual abuse	<i>*We placed the framework in the process category in order to represent the way they look at policies, strategies, activities and challenges. However, some elements may belong to both process and outcome evaluations if we pay attention to the verbatim used by the authors to provide supportive evidence.</i>
<u>Chung et al. [20]</u> CBR-related program content - Advocacy, networking, involvement of relatives and families, of CBR manager, of CBR workers Participant empowerment/governance - Leadership, self-help and mutual help, autonomy in program Community ownership - Community support and recognition, national/government level support, collaboration and support among different sectors Program management and development - Compliance to relevant service standards, ethical practices, management issues, sustainability, continuous growth and development	Participants outcomes Functional independence, education, economic independence, participation in family and community life, physical change, spiritual change, early detection and intervention
<u>Cornielje et al. [13]</u> <i>*Categories originally proposed by Cornielje et al. [21]</i> Locus of power Commitment to involve others Type of response	Restoration of quality of life
<u>Evans et al. [22]</u> Interpersonal quality Technical quality Management quality	—
<u>Mannan and Turnbull [23]</u> —	Quality of life Family quality of life
<u>McColl and Paterson [24]</u> CBR programs - Aims - Beneficiaries - Strategies Supportive structure under CBR - Human resources - Structural resources - Attitudes	—
<u>Mitchell [7]</u> Service delivery Community involvement Technology transfer Organization and management	—

(continued)

Table 2. Continued

PROCESS: Framework categories and measures	OUTCOMES: Framework categories and measures
<u>Pal and Chaudhury [25]</u> —	Parental adjustment - o Feeling of rejection and resettlement - o Positive feelings toward child - o Negative aspects of maternal mental health - o Feelings of guilt and self-blame
<u>Sharma [26]</u> Strengths Weaknesses Opportunities Threats	—
<u>WHO et al. [2]</u> *Examples of outcomes for the 25 elements are available. Here, examples associated with the 5 components are presented. Factors that promote sustainability Effective leadership, partnerships, community ownership, using local resources, considering cultural factors, building capacity, financial and political support.	Health: promotion, prevention, medical care, rehabilitation, assistive devices Ex.: Improved knowledge about good health, health sector awareness, access to health care and rehabilitation services, improved collaboration across sectors. Education: early childhood, primary, secondary and higher, non-formal, lifelong Ex.: Access to learning, accessibility of local schools, awareness of community that people with disabilities can learn, advocacy to facilitate inclusive education. Livelihood: skills development, self-employment, wage employment, financial services, social protection Ex.: Access to skills development, microfinance and social protection, equal work opportunities for women with disabilities, inclusion in poverty reduction strategies. Social: personal assistance, relationships-marriage and family, culture and arts, recreation-leisure and sports, justice Ex.: Access to personal assistance options, individual support plans, informal support for families, training availability for assistants. Empowerment: advocacy and communication, community mobilization, political participation, self-help groups, disabled people's organizations Ex.: Informed choices and decisions, active participation in family and community, removal of barriers in community, creation of groups of people with disabilities.
<u>WHO and IDC [17]</u> Transfer of skills to community level, program activities	Impact on individuals, community mobilization, opportunity for education, opportunity for work, involvement of disabled people
<u>Wirz and Thomas [27]</u> Service delivery: program planning and management, financial and people management, training, sustainability	Maximizing potential: functional independence, education, economic independence, inclusion, leadership roles in the community, participation in/ownership of programs Ex.: Halting progression of impairment, improved mobility, improved ADL, improved communication skills, improved orientation and mobility skills training by parents, mobility aids, hearing aids, removal of physical barriers, reduced attitudinal barriers, special education or inclusive education attendance, skills and work placements acquisition, earnings through income-generation activities and self-employment, availability of credit groups, equal access to community services, leadership roles in the community, management of self-help groups. Environment: family attitudes, family involvement, community attitudes, inclusion of people with disabilities
<u>Zhao and Kwok [18]</u> Evaluation of management: government role, NGO role, other sectors, communities involvement Evaluation of implementation: services in medical rehabilitation, in educational rehabilitation, in vocational rehabilitation	Evaluation of social impacts of CBR: attitude changes

Table 3. Characteristics of the methods of data collection in CBR.

	Suggestions about the characteristics of the methods
Adeoye et al. [19]	Fifteen-statement questionnaire in which participants needed to say if they agreed or not with each on a five-point Likert scale, developed after qualitative interviews in the local community in Uganda. Tools need to be context-specific in order to be valid and useful.
Cornielje et al. [13]	Need to combine qualitative and quantitative methods: "Evaluations should be as systematic and objective as possible; but as participatory and subjective where necessary." (p.40) Best to develop indicators that meet the specific needs of the program.
Chung et al. [20]	Structure interviews and observations using a template of key points that should be evaluated.
Evans et al. [22]	Use of a tracer approach to document the quality of the process of medical rehabilitation within CBR, including individual interviews, observations, and file review. They acknowledge that it requires a lot of concentration and exhaustive note taking.
Kuipers and Harknett [6]	Best to use more than one method and multiple sources to enable triangulation. Participatory techniques are particularly well suited for CBR as they facilitate the participation of people with disabilities.
Mannan and Turnbull [23]	Propose using quality of life scales.
Pal and Chaudhury [25]	Suggest using a parental adjustment measure with a five-point Likert scale. Tools need to be context-specific in order to be valid and useful.
Sharma [29]	Propose that different qualitative methods of data collection can be relevant (ex: interviews, focus groups, nominal groups, diaries, participatory techniques). Good moderators, the use of audiorecording, and homogeneous groups are suggested to optimize the use of focus groups. Individual interviews are frequently used, and allow the gathering of more personalized data although they are time consuming.
Sharma [30]	Recommends using focus groups even more often for evaluation and instrument development.
Sharma [26]	Best to use more than one method to enable triangulation. In the CBR literature, methods used to collect and analyze the information are frequently not explicitly described upon.
WHO and IDC [17]	Qualitative methodologies are relevant and include: focus groups, interviews, observations, document review, questionnaires, nominal groups, videos or photographs analysis, and diaries.
WHO et al. [2]	Best to use more than one method to collect information in order to enable triangulation. Both qualitative and quantitative methodologies are relevant. They suggest choosing from these methodologies: focus groups, interviews, observations, document review, questionnaires, record review, individual assessments, or surveys.
Velema et al. [16]	Proposed two flow charts and tested their use; one to look at service delivery and another one to examine the role of the environment. Concluded that these could be powerful tools to facilitate the process as they covered most elements of the reports. However, they also realized that information about organizational competency, linkages with other programs and sectors, quality of services, sources of incomes, and changes in community attitudes were not picked up by the flow charts, but were often required during program evaluation.
Wirz and Thomas [27]	Mixed methods and quantitative methodologies have a lot of potential to contribute to demonstrating the effectiveness of CBR. Vital need for a bank of quantitative indicators in CBR evaluations.
Zhao and Kwok [18]	Combine qualitative and quantitative methods. Include archival data and first hand field findings. Try to avoid functional assessments methods used in rehabilitation centers (too sophisticated and hard to master by community staff). Methods need to be simple, practical, and easy to use. Provide suggestions of tables focusing on the ability to do the activity or not, in association with the principal difficulty (e.g., hearing).

Table 4. Proposed framework for program evaluation and evaluative research in CBR.

	Relevance of the program: Fit between program and community	Implementation process: How the program actually operates	Outcomes: Desirable and unintended	Cost: Benefit and effectiveness
	Context, policies, attitudes, needs, services	Activities, strategies, strengths, weaknesses, what the program does to be sustainable and efficient	Short, medium, and long term outcomes for: people with disabilities, families, and communities	Costs for achieving a given outcome, for achieving tangible results
CBR Matrix	Health			
	Education			
	Livelihood			
	Social			
	Empowerment			

proper balance between community development and standards for good evaluation and research. Ideally, these guidelines would be based on the evidence found in this systematic review and consensus among a group of experts, and would

suggest a clear, detailed, and empowering process to follow, with clear links to a shared framework and potential methods of data collection. A field validation of the guidelines would be essential to ensure applicability.

Conclusion

In conclusion, we strongly believe that it is more than time for the CBR community to engage in program evaluation and in the production of best practice guidelines for accountable and empowering evaluations. Since moderate levels of evidence in favor of particular practices are available, experts in program evaluation in CBR need to come to a consensus on what are best evaluative practices in the context of CBR. Further research and evaluation on the conditions under which CBR programs are most effective for different populations is definitely needed, in the respect of both CBR principles and standards for effective research and evaluation. Hopefully, these can be situated within the framework proposed in this manuscript. We wish that this review provided guidance on how to demonstrate the effectiveness of this strategy, in order to foster the institutionalization of existing CBR programs showing positive results and the development of new CBR programs to address the needs of the population living with a disability in resource-poor areas.

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Declaration of interest

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Appendix A

Table A1. Characteristics of the included articles and highlights of the quality assessments.

Article	Type of article	Objective	Methods	Rating: consensus (tool)	Highlights of the quality assessment	
					Congruence with evaluation and research standards	Congruence with CBR principles
Adeoye et al. [19]	Observational study (qualitative)	Develop an evaluation tool for CBR	Qualitative analysis of core elements from the joint position statement (JPS, 2004) Followed by a case study in Uganda (interviews, focus groups, document review).	CASP: 8/10	(-) Tool is only useful in one specific context in Uganda (-) Little information about the actual tool (+) Feasible to implement (+) Accurate in local context	(+) Grounded in CBR values and terminology through the JPS (+) Participation of the local community
Boyce and Ballantyne [5]	Editorial	Suggest ways to develop CBR through evaluation	X	X	(-) Accuracy: Not consensus among a group of experts, nor opinion of respected authorities (-) Only tested in China, little generalization possible	(+) Process suggested is coherent with CBR values of inclusion, participation and empowerment (+) Development process is congruent with inclusion and participation
Chung et al. [20]	Observational study (qualitative)	Development of a framework for CBR evaluations in China	Qualitative analysis of core elements of CBR defined from key texts and reports of CBR evaluations Tested for relevance and appropriateness in five Chinese CBR programs (interviews, observations, document review)	CASP: 9/10	(-) Accuracy: Not consensus among a group of experts, nor opinion of respected authorities (-) Only tested in China, little generalization possible	(+) Process suggested is coherent with CBR values of inclusion, participation and empowerment (+) Development process is congruent with inclusion and participation
Cornielje et al. [13]	Editorial	Share lessons learned during evaluations of CBR programs	X	X	(+) Lessons learned based on more than one experience (-) Accuracy: Not consensus among a group of experts, nor opinion of respected authorities (+) Accuracy: propose to combine objective and subjective measures (-) Lack of clarity in the article (-) Not totally clear if the tracer approach was developed and/or tested with CBR programs or other types of rehabilitation services (-) Poor methodology (relied on old search, inclusion and exclusion criteria are not clear, no quality assessment for the included articles) (-) Lack of integration of the findings of the different articles reviewed	(+) Lessons are coherent with CBR philosophy (+) Relevance to the field of CBR and respectful of context (low-cost) (+) Relevance of study to the field of CBR
Evans et al. [22]	Observational study (qualitative)	Propose tracer approach to evaluate quality of CBR medical rehabilitation	Application of the method in West Bengal, India (document review, observations, interviews)	CASP: 7/10	(-) Accuracy: Not consensus among a group of experts, nor opinion of respected authorities (+) Accuracy: propose to combine objective and subjective measures (-) Lack of clarity in the article (-) Not totally clear if the tracer approach was developed and/or tested with CBR programs or other types of rehabilitation services (-) Poor methodology (relied on old search, inclusion and exclusion criteria are not clear, no quality assessment for the included articles) (-) Lack of integration of the findings of the different articles reviewed	(+) Relevance to the field of CBR and respectful of context (low-cost) (+) Relevance of study to the field of CBR
Finkenflugel et al. [28]	Literature review	Examine the classification models used for evaluations in CBR	Used search results of previous study [4] and complemented with other documents	AMSTAR: 3/11	(-) Accuracy: Not consensus among a group of experts, nor opinion of respected authorities (+) Accuracy: propose to combine objective and subjective measures (-) Lack of clarity in the article (-) Not totally clear if the tracer approach was developed and/or tested with CBR programs or other types of rehabilitation services (-) Poor methodology (relied on old search, inclusion and exclusion criteria are not clear, no quality assessment for the included articles) (-) Lack of integration of the findings of the different articles reviewed	(+) Relevance to the field of CBR and respectful of context (low-cost) (+) Relevance of study to the field of CBR
Finkenflugel et al. [4]	Literature review	Establish the evidence base for CBR	Search in five databases from 1978–2002 Only articles in English and reporting CBR experiences in low- and middle-income countries	AMSTAR: 5/11	(+) Comprehensive search (-) Poor account of the quality of included articles	(+) Clear relevance for the field of CBR (-) Confusion between CBR and rehabilitation in the community showed in the included articles
	Editorial		X	X		

(continued)

Table A1. Continued

Article	Type of article	Objective	Methods	Rating: consensus (tool)	Highlights of the quality assessment	
					Congruence with evaluation and research standards	Congruence with CBR principles
Kuipers and Harknett [6]		Contribute to the debate about evidence-based practice in CBR			(–) Does not present consensus among a group of experts, nor opinion of respected authorities (–) Arguments for their propositions are weak	(+) Congruent with CBR values and the context of its implementation
Mannan and Turnbull [23]	Literature review	Examine literature on evaluations in CBR	Not provided (search, inclusion criteria)	AMSTAR: 2/10	(–) Search strategy and inclusion criteria are not provided (+) Utility: suggestion of tools for outcome measurement (+) Rigorous development and involvement of stakeholders from different programs	(+) Congruence of propositions with CBR the need to include people with disabilities and their families (+) Relevance for CBR (–) Now that CBR guidelines provide clear definitions for matrix, less relevant
McColl and Paterson [24]	Observational study (qualitative)	Develop a framework for CBR programs	Key informants representing CBR programs were interviewed	AMSTAR: 8/11		
Mitchell [7]	Literature review	Review research on CBR	Not provided (search, inclusion criteria)	AMSTAR: 1/11	(–) Methodology for the review is not provided (+) Suggestions congruent with utility and propriety evaluation standards (reporting the results)	(+) Relevance and coherence of propositions with current CBR definitions
Pal and Chaudhury [25]	Observational study (quantitative)	Develop an instrument to measure parental adjustment in a CBR program in India	Development of the measure from attitude statements heard in the area Interviews with parents of children attending the program using these statements to which they answered using a five-point Likert scale	STROBE: 16/22	(+) Accuracy: Rigorous analysis (–) Accuracy: Further validation is needed (–) Utility: Generalization is limited as the tool is relevant to the Indian rural context only	(+) Congruence with bottom-up approach in CBR as it is grounded in local experience
Price and Kuipers [14]	Editorial	Propose action research as suitable for CBR evaluations	X	X	(–) Accuracy: Does not present consensus among a group of experts, nor opinion of respected authorities (+) Excellent respect of the utility standard as the goal is program improvement	(+) Congruence with CBR values of participation and empowerment and its context (+) Proposition promotes local acceptability and empowerment
Sharma [29]	Literature review	Review literature on the role of qualitative approaches in CBR evaluations	Not provided (search, inclusion criteria)	AMSTAR: 0/11	(–) Methodology for search is not described (+) Feasibility of using qualitative methodologies in CBR evaluations (+) Utility of qualitative approaches to gather the perspectives of people (+) Relevance of review to give insights into data collection methods	(+) Congruence of proposition with context of implementation of CBR
Sharma [30]	Literature review	Examine the extent to which focus groups have been used in CBR	Search on MEDLINE, inclusion and exclusion criteria provided.	AMSTAR: 2/11		(+) Using focus groups for evaluation and intervention is congruent with empowerment (–) Inclusion of many articles associated with rehabilitation programs in the community (+) Congruence of suggestions with CBR values of
Sharma [26]	Literature review	Analyze the extent to which CBR has been evaluated	Search on MEDLINE, for CBR and evaluation.	AMSTAR: 3/11		

Thomas [15]	Editorial	Contribute to debates around CBR and present the CBR Guidelines	Qualitative analysis using a framework of Strengths, Weaknesses, Opportunities and Threats (SWOT) X	X	(+) Suggestions congruent with scientific standards (-) Review is restricted to one database (-) Does not present consensus among a group of experts, nor opinion of respected authorities (-) All reports studied from evaluations conducted by the authors (+) Utility of flow charts to structure data collection and gather most relevant information	(+) Confusion between CBR and rehabilitation in the community showed in the included articles (+) Relevance of propositions for optimal use of the Guidelines (+) Relevance of suggesting a tool to structure the evaluative process (-) Lack of clear distinction between rehabilitation programs in the community and CBR
Velema et al. [16]	Observational study (qualitative)	Validate the use of flow charts in evaluations of CBR programs	Comparison of information reported in five program evaluations reports with information that can be collected with flow charts	CASP: 7/10		
WHO and IDC [17]	Guidelines	Produce guidelines on self-assessment and monitoring of CBR	Not clear: based on key texts and mention that they were prepared with the collaboration of the WHO and IDC	AGREE II global rating: 2/7	(+) Scope and purpose of guidelines clearly described and relevant (-) Weak methodology to produce the guidelines	(+) Self-reflection for assessment is congruent with empowering programs to take the lead of their evaluations
WHO et al. [2]	Guidelines	Strengthen CBR programs	Based on consensus among a group of experts on the CBR matrix which provided the structure At least two authors involved for each section Extensive field validation	AGREE II global rating: 5/7	(-) Not sufficiently grounded in evidence (-) Section on program evaluation is limited (+) The views of people with disabilities have been sought (propriety) and emphasize the importance of sharing findings and taking action (utility)	(+) High relevance for CBR implementation (+) Clear definitions and structured around a potential common matrix (+) Grounded on experience around the world (+) Accessible in 3 languages
Wirz and Thomas [27]	Observational study (qualitative)	Review usefulness of indicators proposed in CBR evaluations	Review planned in 2020 Two authors read 10 evaluation reports (both published and privately circulated) Analyzed the information included to generate categories and indicators.	CASP: 7/10	(+) Rigorous analysis by two independent authors (-) Choice of evaluation reports is not explained	(-) Propose indicators associated with only 1/3 dimensions (+) Bank of indicators can be useful to CBR evaluations (-) Now that CBR guidelines provide clear definitions for matrix, less relevant
Zhao and Kwok [18]	Guidelines	Provide guidance for accountable evaluations	Reviewed key texts from the literature and consulted colleagues and people with disabilities.	AGREE: 3/10	(-) Not clear how best practices were generated (+) Suggestions are congruent with utility, feasibility, accuracy standards for evaluation	(+) Proposition concerning self-assessment is congruent with the participation and empowerment principles

Appendix B

List of excluded studies (available upon request sent to corresponding author).

3.2 A Review of Suitable Program Evaluation Approaches: What Can CBR Learn from the Evaluation World?

The program evaluation literature can offer indications as to how CBR program evaluation should be conducted. In this section, an overview of nine evaluation approaches is presented. Each provides directions that can be useful in determining best practices in CBR program evaluation: four offer key principles (Centers for Disease Control and Prevention [CDC], 1999; Fetterman & Wandersman, 2005; Mertens, 2009; Patton, 2012), two suggest a sequence of steps (CDC, 1999; Green & Kreuter, 2005), two relate to data collection methods (Bamberger, Rugh, & Mabry, 2012; Chevalier & Buckles, 2013a), and three explore the use of frameworks (Chen, 2005; Green & Kreuter, 2005; Rossi, Lipsey, & Freeman, 2004).

3.2.1 Empowerment evaluation (Fetterman & Wandersman, 2005). Fetterman & Wandersman define empowerment evaluation as:

an evaluation approach that aims to increase the probability of achieving program success by (1) providing program stakeholders with tools for assessing the planning, implementation, and self-evaluation of their program, and (2) mainstreaming evaluation as part of the planning and management of the program/organization. (p.28)

This approach draws on the evaluation process and results to inform program improvement and build local evaluative capacity. This is congruent with CBR core values, as it fosters buy-in and empowerment, two areas poorly documented in the CBR evaluation literature. The authors propose ten guiding principles to ensure evaluation decisions are aligned with ideals of capacity building and self-determination: improvement, community ownership, capacity building, organizational learning, social justice, inclusion, democratic participation, community knowledge, evidence-based strategies and accountability (Fetterman & Wandersman, 2005). Improvement is associated with the desire to make positive change in people's lives through the

evaluation, while social justice highlights the commitment to improve the conditions of the most disadvantaged. In order to achieve such change, empowerment evaluation values the inclusion of representatives from all groups and from all levels, as well as democratic participation where everyone has the opportunity to share their opinions. The principle of community ownership implies that the decision-making power should remain in the hands of local stakeholders and that they should eventually assume different evaluation roles. Thus, in empowerment evaluation, local representatives learn how to conduct evaluations and engage in a reflective culture in which data are used to inform decisions. In that spirit, Fetterman and Wandersman suggest that evaluators should act as critical friends for the program, as opposed to experts. Evidence-based strategies are valued and used to inform program planning and evaluation, but they are always contextualized using community knowledge and experience. The last principle is accountability and consists of the generation of data showing the actual outcomes of the program for internal and external audiences. This evaluation approach provides useful guidance as to how to make CBR evaluation inclusive and empowering.

3.2.2 Transformative evaluation (Mertens, 2009). The second approach examined is transformative evaluation. It aims at improving social justice by giving a voice to those who are marginalized. Inclusion of all stakeholders, especially those perceived to hold less power, is seen as key to challenge social oppressive structures. Questions of power and privilege are explicitly addressed after trust has been built between evaluators and local representatives. Individuals who are usually disadvantaged help determine the evaluation focus and questions. Transformative evaluation is particularly relevant to tailor evaluations to cultural complexities as context, history and culture associated with race, ethnicity, disability, poverty, gender and age are valued and explored. Although qualitative or quantitative methods can be used, mixed methods are

considered especially relevant to incorporate community perspectives and quantitative indicators of change into the inquiry process. Transformative evaluation appears particularly informative in respect to the inclusion of disabled individuals in CBR program evaluation processes conducted in diverse cultural settings and in relation to how this may foster greater social justice.

3.2.3 Utilization-focused evaluation (Patton, 2012). Patton proposes an utilization-focused evaluation, a process aimed at fostering program evaluation use through close collaboration with the individuals identified as the primary intended users of evaluation findings. The major focus is to foster the use of the process and findings by working very closely with these primary intended users in an iterative learning journey. They are expected to contribute to decisions associated with evaluation questions and methods. Concerned with social justice, the author emphasizes the importance of enabling the participation of the least powerful in the community, of stimulating evaluative thinking within an organization and of building evaluation capacity. This collaborative approach appears especially informative to facilitate participation and empowerment of people with disabilities through CBR program evaluations.

3.2.4 Health program planning and evaluation (Green & Kreuter, 2005). Green and Kreuter also highlight the importance of closely collaborating with the local community when conducting a health program evaluation to enhance the likelihood for evaluation findings to be credible to the intended audience. Their framework is known as the PRECEDE-PROCEED model, which spells out as Predisposing, Reinforcing, and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation - Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development. It has been used extensively in health promotion planning and evaluation. The model includes a detailed sequence of steps divided in four categories: needs assessment, program implementation, implementation

evaluation and outcome evaluation. To keep evaluations manageable, the authors recommend focusing at first on a small component of the program and measuring only two or three outcomes. This comprehensive framework can be useful to understand how biological, behavioural, environmental and educational factors can affect a population's health and can be addressed in CBR program planning and evaluation. It can also facilitate the analysis of all the elements that may predispose individuals to adopt a specific lifestyle or accept detrimental living conditions, or that may facilitate or reinforce it. PRECEDE-PROCEED can therefore help analyze the factors leading to the participation or exclusion of people with disabilities in their communities, and whether CBR programs are effective at addressing these issues.

3.2.5 Framework for program evaluation in public health (CDC, 1999). The CDC's (1999) framework was developed for health programs and promotes the incorporation of evaluation activities into an organization's routine. It provides essential directions for CBR evaluation with its practical, realistic and collaborative step-by-step approach to evaluation and its clear standards of good evaluative practices, two poorly documented areas in CBR evaluation. It stipulates that program evaluations should include six steps: 1) engaging stakeholders, 2) describing the program, 3) focusing the evaluation design, 4) gathering credible evidence, 5) justifying conclusions, and 6) ensuring use and sharing lessons learned. This framework highlights the importance of developing feedback loops throughout the evaluation to ensure findings lead to program improvement. It also makes the case for a collaborative approach to reduce program stakeholders' apprehensions and increase the likelihood that results will be used. Four evaluation quality standards are suggested: utility (i.e. satisfying information needs in time), feasibility (i.e. relying on viable and pragmatic procedures that are not too disruptive), propriety (i.e. respecting laws and ethics, with the welfare of those involved or who can be

affected in mind), and accuracy (i.e. generating valid and reliable findings). These provide guidance as to how the autonomy of people with disabilities should be respected during an evaluation and how to design sustainable CBR evaluation, while calling for more attention on the accuracy of conclusions from CBR program evaluations.

3.2.6 Evaluation Hierarchy (Rossi et al., 2004). Rossi and colleagues provide further indications regarding the sequence in which evaluations must be conducted for conclusions to be accurate. They highlight that each component must rest on appropriate analyses and argue that interpretations from an impact assessment might not be accurate if there has been no analysis of how the program was designed and is actually implemented. Figure 3.1 illustrates the Evaluation Hierarchy they proposed, where the element on the left represents the first element to be evaluated. Their structure suggests that a program evaluation must first examine whether program activities match community needs, then look at program design and implementation, and only after at outcomes, impact and costs. I selected this approach because I felt that it filled a gap in the CBR evaluation literature regarding the evaluation focus and the sequence of steps included in an evaluation to generate well-founded conclusions. It is also congruent with preoccupations that emerged from the preliminary field visit in South Africa, including donors' pressure for cost analyses and the need for strategic analyses to ensure program activities target unmet needs.

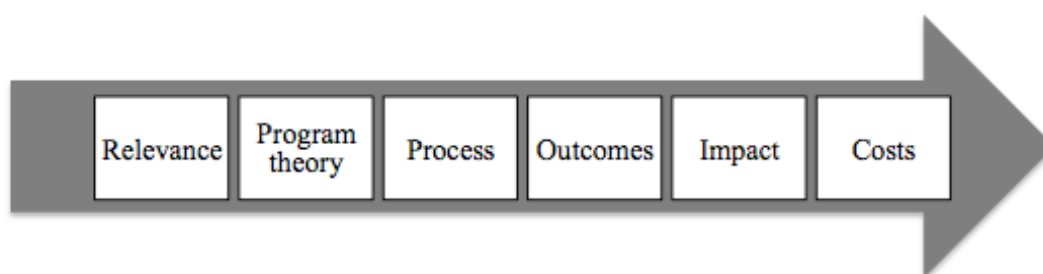


Figure 3.1. Evaluation Hierarchy. Adapted from Rossi et al. (2004, p.80): key words are used to represent each level and an arrow is represented instead of a ladder.

3.2.7 Theory-driven evaluation (Chen, 2005). Another approach that can be used to contextualize CBR evaluation to program needs is theory-driven evaluation. Chen does not support a specific method over another, but rather suggests that it is the program's theory that should guide evaluation decisions. Program theory is defined as "a configuration of the (...) assumptions held by stakeholders and thus underlying the programs stakeholders create" (p.16). The evaluation then documents whether or not the assumptions are correct and the extent to which the program has generated the expected outcomes. In this approach, the evaluator acts as a facilitator that helps program stakeholders draft or review their logic models and test them. Given the wide range of CBR programs and varied contexts in which they are implemented, I thought Chen's approach could be useful to clarify what programs intend to do and are doing in order to foster reflective thinking about the program, while generating clear descriptions of program goals, activities and expected outcomes.

3.2.8 Real-World evaluation (Bamberger et al., 2012). Bamberger and colleagues offer several suggestions to contextualize evaluations. They advise evaluators to collaborate closely with key local stakeholders, who are ideally positioned to adapt proposed formats to real-world constraints, thus enhancing sustainability. They also recommend to first identify the type(s) of constraints that need to be addressed (i.e. budget, time, data or political) and propose changes associated with sample size, methods, design and sources of data. Examples of strategies proposed in Real-World evaluation follow in Table 3.1.

Table 3.1

Real-World Evaluation Strategies to Address Evaluation Constraints

Budget constraints	Time constraints	Data constraints	Political influences
Simplify evaluation design	Use the solutions proposed for budget constraints (column on the left)	Reconstruct baseline data (e.g. using secondary data, timeline exercise with critical incidents)	Ensure appropriateness and comprehensiveness of evaluation even when pressured by funding agencies or clients
Rationalize data needs to remove nonessential information	Conduct videoconferences prior to site visit	Change comparison groups	Address the concerns of stakeholder groups
Look for reliable secondary data	Hire more data collectors	Use multiple data collection methods for sensitive topics or harder-to-reach groups	Address all issues raised in the evaluation, not only those asked by the funding agency
Favour low-cost data collection methods (e.g. focus groups instead of individual interviews)	Revise data recording procedures with staff	Use multiple methods	
Train university students to collect data	Use technology to collect data (e.g. pictures, software, recorders)		

* Note: Adapted from Figure 1.1 in Bamberger et al. (2012, p.5): 1) table format and words used were modified; and 2) other relevant solutions discussed in their book added.

3.2.9 Social Analysis Systems² (Chevalier & Buckles, 2013ab). Chevalier and Buckles propose numerous tools and techniques to collect data and foster grassroots participation in program planning, evaluation and Participatory Action Research (PAR). These include: active listening and participative brainstorming, ranking, rating and sorting exercises used to gather stakeholders' opinions. Local communities identify and prioritize their own needs, choose their

partners, and select the best options available. Social Analysis Systems² (SAS²) can therefore facilitate the active participation of people with disabilities in CBR program evaluations.

3.3 Initial Proposition for Best Practices in CBR Program Evaluation

The literature review provides key insights into how to best evaluate programs in regard to core features of sound CBR evaluation, necessary steps, suitable methodologies, and frameworks for CBR evaluation.

3.3.1 Key features and steps for CBR program evaluation. Firstly, I describe seven features of sound CBR program evaluation in Table 3.2. As recommended by Chen (2005), I used theories from CBR and program evaluation to develop this model. I suggest that the six CBR Principles (WHO, UNESCO, ILO, & IDDC, 2010), first introduced in Chapter 1, can be used to guide CBR program evaluation. These are: autonomy, inclusion, participation, empowerment, sustainability and multisectoral collaboration. The review of suitable evaluation approaches also indicates that accuracy (CDC, 1999; Rossi et al., 2004) needs to be added as a seventh feature of sound CBR evaluation. Insights from the systematic review on CBR evaluation and from program evaluation theories enabled me to describe how these principles can be applied to CBR program evaluation.

Secondly, based on the review conducted, an eight-step process for CBR evaluation is suggested (CDC, 1999; Boyce & Ballantyne, 2000; Mitchell, 1999; Price & Kuipers, 2000; WHO & IDC, 1996; WHO, UNESCO, ILO, & IDDC, 2010; Zhao & Kwok, 1999). These eight steps are described in Table 3.3 based on findings from the literature review. Congruent with PAR, the process must be iterative and integrate feedback loops to maximize the use of gathered evidence in decision-making and to lead to CBR programs improvement (CDC, 1999; Patton, 2012; McNiff & Whitehead, 2009).

The review of suitable evaluation approaches highlights the importance of collaborating very closely with local stakeholders throughout the evaluation process in order to make the evaluation process and findings as useful as possible (Fetterman & Wandersman, 2005; Green & Kreuter, 2005; Patton, 2012). At the beginning of the process, it is therefore crucial to build a relationship with key local stakeholders, foster evaluative thinking and stimulate their active engagement in the evaluation. The literature review clearly highlighted the importance of establishing common evaluation priorities and processes (Boyce & Ballantyne, 2000; CDC, 1999; Patton, 2012, WHO, UNESCO, ILO, & IDDC, 2010; Zhao & Kwok, 1999), thus addressing explicitly local stakeholders' most critical issues, and maximizing relevance and ulterior use of the data collected. Concerning the data collection plan, while qualitative methods have been used extensively and remain relevant for CBR, there is a call to integrate mixed methods more often and include the perspectives of multiple actors to strengthen evaluation conclusions (Cornielje et al., 2008; Wirz & Thomas, 2002, Zhao & Kwok, 1999). Participatory tools can also be considered in order to enable people who are less literate, disabled or marginalized, to share their opinions on the program (Chevalier & Buckles, 2013b; Kuipers & Harknett, 2008; Sharma, 2004). The systematic review on CBR evaluation highlighted divergent views regarding the use of locally generated indicators and universal indicators allowing for cross-comparisons (Adeoye et al., 2011; Chung et al., 2011; Wirz & Thomas, 2002).

Table 3.2

Key Features of Best Practices in CBR Program Evaluation

Features	Description
Respect autonomy	All are free to participate or not (CDC, 1999). Representatives from the local community, including people with disabilities should make the decisions concerning the evaluation process (Fetterman & Wandersman, 2005; Patton, 2012).
Include all	The perspective of all community members affected by the program should be sought, including people with disabilities and other disadvantaged groups. Care should be taken to include representatives from the different groups in the community, embracing diversity of race, ethnicity, age, disability, gender and religion (Fetterman & Wandersman, 2005; Mertens, 2009).
Enable participation	Conditions enabling all to express their opinions freely and to engage actively in the evaluation should be present. This can include the use of participatory activities in which people are asked to vote or share their thoughts on the program and may demand attention to linguistic differences and power dynamics (Chevalier & Buckles, 2013ab; Fetterman & Wandersman, 2005; Mertens, 2009).
Empower	Potential empowering strategies may include: the fostering of a reflective culture in which results are used to inform decisions, having evaluators act as critical friends (Fetterman & Wandersman, 2005), providing coaching and training in program evaluation (Boyce & Ballantyne, 2000), and closely collaborating with those most likely to use the results. The local community should control both process and data utilization (Patton, 2012).
Be sustainable	To limit external dependency, the design of sustainable, manageable evaluations should take into account local resources and constraints. Study design, data collection methods and sample sizes should follow sustainability principles (Bamberger et al., 2012).
Embrace a collaborative process	A collaborative evaluation process between evaluators and program stakeholders enhances evaluation use (Bamberger et al., 2012; Green & Kreuter, 2005; Patton, 2012).
Be accurate	Conclusions about must rest on appropriate analyses, starting from program relevance, and moving on to process, outcomes and cost-analyses (Green & Kreuter, 2005; Rossi et al., 2004). To improve accuracy, one should rely on: a logic model to clarify and test program assumptions (Chen, 2005), mixed methods (Cornielje et al., 2008; Wirz & Thomas, 2002; Zhao & Kwok, 1999), and multiple data sources (Bamberger et al., 2012; Chung et al., 2011; Evans et al., 2001; Kuipers & Harknett, 2008; Sharma, 2007; WHO, UNESCO, ILO, & IDDC, 2010; Zhao & Kwok, 1999).

Table 3.3

Steps in a CBR Program Evaluation Process

Steps	Description
1. Engage stakeholders in the evaluation	- Identify primary users of evaluation results (Patton, 2012). - Select the evaluation team members (CDC, 1999), including people with disabilities, their families, as well as people involved or affected by the program at different levels (Boyce & Ballantyne, 2000; Price & Kuipers, 2000). - Cast evaluators as critical friends, to build trust with local stakeholders and increase buy-in in program evaluation training (Fetterman & Wandersman, 2005; Mertens, 2009).
2. Describe the program within its context	- Develop a good understanding of the program's context, needs, objectives, target population, activities, and resources (CDC, 1999). - Design a logic model to clarify goals and expected outcomes (Chen, 2005).
3. Decide on the focus of the evaluation	- Clarify evaluation purpose and questions with intended users (e.g. relevance, efficiency, effectiveness, impact, sustainability) (Boyce & Ballantyne, 2000; WHO, UNESCO, ILO, & IDDC, 2010; Zhao & Kwok, 1999). - Situate questions within a shared framework combining the CBR Matrix (ILO, UNESCO, & WHO, 2004) & the Evaluation Hierarchy (Rossi et al., 2004). - Rely on the <i>CBR Guidelines</i>' desirable outcomes (WHO, UNESCO, ILO, & IDDC, 2010) to identify potential outcome measures. Document outcomes for people with disabilities themselves (on health status, educational achievement, livelihood opportunities, social opportunities, and empowerment), as well as outcomes for the program setting (social, institutional, physical, political, economic) (Wirz & Thomas, 2002). - Limit initial data collection to two or three key outcome measures (Green & Kreuter, 2005).
4. Plan the data collection	- Collaboratively discuss and select study design, methods and sources of data collection, data collectors, and time frame (CDC, 1999; WHO, UNESCO, ILO, & IDDC, 2010). - Adapt process to local context and work hand in hand with key local stakeholders (Bamberger et al., 2012; Patton, 2012). - Prepare data collection scripts (CDC, 1999).
5. Collect the information	Collect data according to plan (CDC, 1999; WHO, UNESCO, ILO, & IDDC, 2010).
6. Analyze the information	Make sense of the information collected: structure and organize qualitative data into themes and identify tendencies in quantitative data (CDC, 1999; WHO, UNESCO, ILO, & IDDC, 2010).
7. Share findings	- Share findings with the local community through reports or meetings (WHO, ILO, UNESCO, IDDC, 2010). - Share findings with donors and partners (WHO, UNESCO, ILO, & IDDC, 2010). - Share findings with the scientific community: publish in scientific journals or present in conferences (WHO, UNESCO, ILO, & IDDC, 2010).

3.3.2 Using a framework in CBR evaluation. The CBR evaluation framework first introduced in the systematic review (Grandisson, Hébert, Thibeault, 2014) provides a common language for carrying evaluations and anchors each step of the process in iterative analysis of the data previously collected (Green & Kreuter, 2005; Rossi et al., 2004). I reiterate here one of our conclusions, namely that the CBR Matrix (ILO, UNESCO, & WHO, 2004b) be part of this framework since it formally adds the voices of those who generated it, and since all its inherent features are operationalized in the *CBR Guidelines* along with desirable outcomes (WHO, UNESCO, ILO, & IDDC, 2010). It also conceives of CBR as a community development strategy requiring collaboration across sectors. The Evaluation Hierarchy (Rossi et al., 2004) could also complement the CBR evaluation framework, given its focus on maximum goodness of fit between community needs and program activities, processes, outcomes, impacts and costs. The framework, presented in Figure 3.3, could act as a menu in which people would situate CBR evaluation on both axes, i.e. the CBR Matrix component(s) and element(s) evaluated, and the main issues addressed (i.e. relevance, process, outcomes, or costs). The suggested framework was tested in the field in Chapter 4 and validated with experts in Chapter 5 to ensure that it is clear, comprehensive, acceptable to the CBR community, and applicable to the context in which CBR programs are implemented.

		Relevance: <i>Fit between program and community</i>	Process: <i>How the program actually operates</i>	Outcomes: <i>Desirable and unintended</i>	Costs: <i>Benefit and effectiveness</i>
		Context, policies, attitudes, needs, services	Activities, strategies, strengths, weaknesses, what the program does	Short, medium, and long term outcomes for: people with disabilities, families, communities	Costs for achieving a given outcome or costs for achieving tangible results
CBR Matrix	Health				
	Education				
	Livelihood				
	Social				
	Empowerment				

Figure 3.3. Initial proposition: Common framework for CBR program evaluation. *Reproduced with permission, from: Grandisson, Hébert, et al. (2014).

3.4 Conclusion

The literature review identified several characteristics of sound CBR program evaluation, which led to the development of a best practice model for CBR program evaluation. The model generated is based on the principles at the heart of this community development strategy (WHO, UNESCO, ILO, & IDDC, 2010) and defines how these could be applied to evaluation using insights from the systematic review on CBR program evaluation and the analysis of suitable evaluation theories. Surprisingly, only one article had suggested that CBR evaluations should aim to empower local communities (Boyce & Ballantyne, 2000). Yet, this appeared inescapable to the author if best practices for CBR evaluation are to reflect CBR philosophy. Fortunately, empowerment evaluation theory (Fetterman & Wandersman, 2005) provides clear directions on how to achieve this goal. Evaluation theories emphasize the necessity for close collaboration

with local stakeholders to foster evaluation process and findings use, and the importance of giving a voice to those who are marginalized (Bamberger et al., 2012; Fetterman & Wandersman, 2005; Green & Kreuter, 2005; Mertens, 2009; Patton, 2012). Regarding methods, findings suggest that mixed methods and participatory tools could be relevant for CBR program evaluation (Chevalier & Buckles, 2013a; Cornielje et al., 2008; Kuipers & Harknett, 2008; Sharma, 2004; Wirz & Thomas, 2002; Zhao & Kwok, 1999). Findings also highlight diverging views on to the use of context-specific or universal data collection tools and indicators in CBR (Adeoye et al., 2011; Chung et al., 2011; Thomas, 2011; Wirz & Thomas, 2002).

In regard to the use of frameworks to situate findings from CBR evaluations, none of the 13 retrieved in the systematic review appeared to have gained consensus, and to be sufficiently comprehensive, clear, applicable, and representative of CBR today. Thus, a new framework was developed to facilitate exchanges between programs and yield a solid and more cohesive evidence base for CBR effectiveness. This framework combined the CBR Matrix (ILO, UNESCO, & WHO, 2004b) and the Evaluation Hierarchy (Rossi et al., 2004). While the literature review was an essential starting point to identify key features of best evaluative practices in CBR, the model and framework presented in this chapter were refined in the subsequent two research phases: they were tested in the field with a CBR program (Chapter 4) and validated with experts (Chapter 5).

Chapter 4: Community-Based Rehabilitation Program Evaluation: Lessons Learned in the Field

Applicability and stakeholder involvement are two core dimensions of best practice guidelines quality (AGREE Next Step Consortium, 2009). This entails that the guidelines developed for CBR program evaluation must be manageable to implement in a range of CBR contexts and represent the views of those most actively involved, namely CBR beneficiaries and practitioners in low- and middle-income countries. To achieve this, and to gain a more substantial knowledge of challenges and opportunities in CBR evaluation, a pilot study was carried with a South African non-governmental organization (NGO), *Goedgedacht*. This second step of my doctoral research process also enabled me to test and refine the initial best practice model and framework in a real-life scenario.

Goedgedacht provides services to farm workers' children from Malmesbury, in the Western Cape. Foetal alcohol spectrum disorder (FASD) is highly prevalent in this region, with children from rural areas at increased risk, and farm workers' children being the most vulnerable to FASD in all its forms, including the most severe (Viljoen et al., 2005). The burden of FASD on South African farms is due to a wide range of factors: low socioeconomic status, low educational attainment, social pressure to consume alcohol, lack of recreational activities, high availability of alcohol, being born in families with several generations of heavy drinkers, and culture of alcohol abuse in which binge drinking has become the norm (London, 1999; May et al., 2008; Viljoen et al., 2005). Many of these are the legacy of the now illegal 'dop system', which prevailed for over 300 years and consisted of the partial or full payment of farm workers in alcohol (London, 1999). It is beyond the scope of this thesis to explain all the mechanisms underlying the high FASD prevalence in farm workers' children in the Western Cape.

Nonetheless, it is crucial to understand that FASD is deeply rooted in the history and culture of

this community and thus, simple health education programs targeting pregnant women would clearly be insufficient. *Goedgedacht* attempts to break the cycle of poverty in farm workers and their families by focusing on children, supporting them from a very young age and until they reach adulthood. The *Path Out of Poverty* program, operated by this NGO, is composed of several components designed to help these children complete their education, advocate for themselves and be ready for employment, and to reduce the number of babies born with FASD. These include an early childhood development (ECD) centre, after-school support, personal development sessions, health promotion workshops for parents, safe houses on farms, and community outreach. Food and health education are also provided throughout the different projects. The NGO did not have formal links with the government at the time of the study. To fund their different activities, the NGO operates a farm in which olive trees are grown and relies on multiple donors such as Comic Relief and Nelson Mandela Foundation.

The present study is part of a long-term partnership between Rachel Thibeault and *Goedgedacht*. The first field visit in February 2011 enabled the Canadian partners to familiarize themselves with the program and the local reality. It also provided an opportunity to get to know our partners and to establish common evaluation priorities and processes. This corresponds to the three steps preceding data collection planning in the best practice model presented in Chapter 3. The second visit in April 2012 focused on the evaluation of the ECD program for children up to 6 years of age, and is the only one included in this thesis. More details about the ECD project are provided in the logic model presented in Figure 4.1.

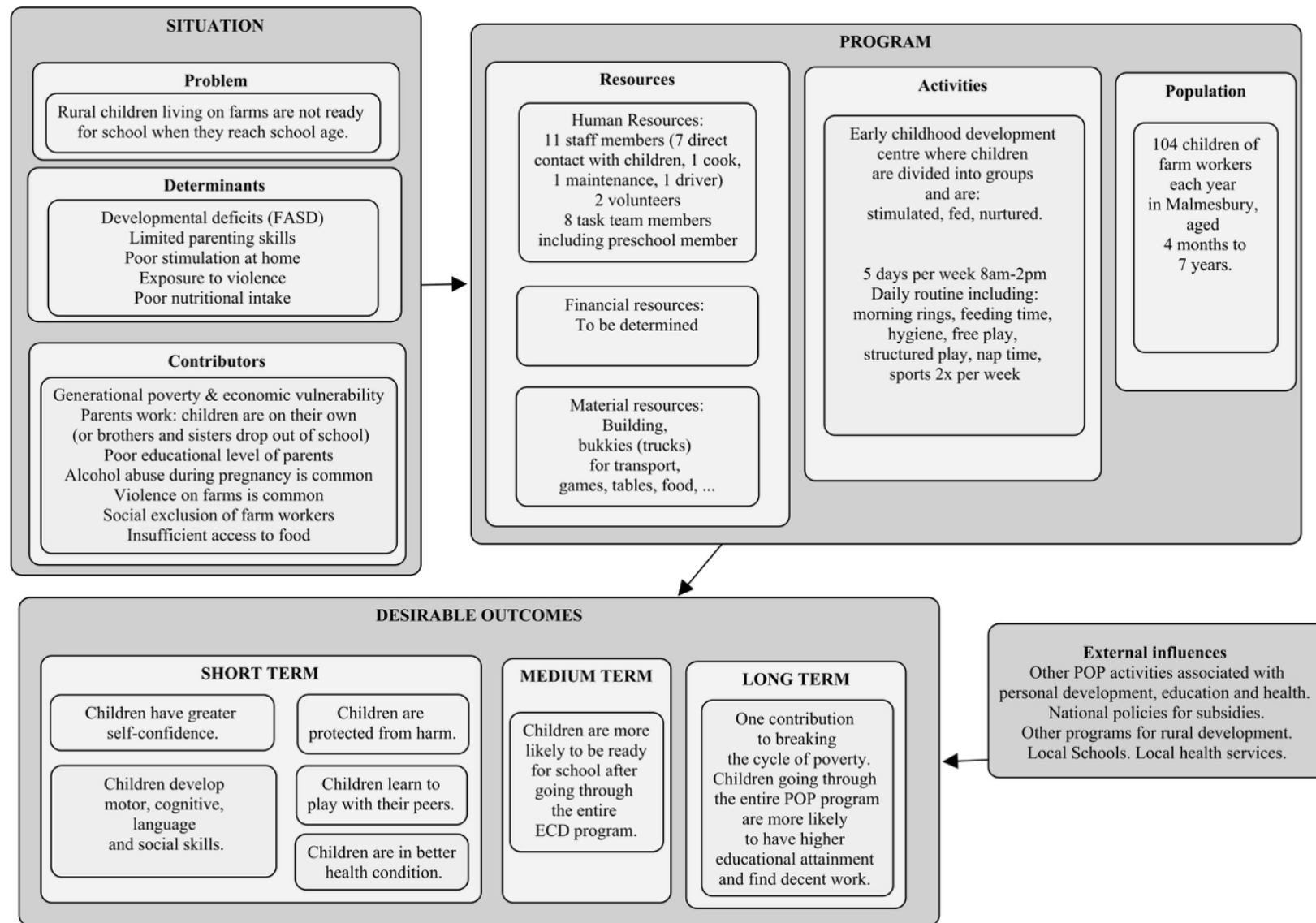


Figure 4.1. Logic model: Goedgedacht's early childhood development project.

This chapter presents the field study during which we evaluated the above-mentioned CBR program and used the process to draw lessons on suitable strategies for CBR evaluation. This experience allowed me to pilot my initial best practice model since it highlighted a range of sound CBR evaluation strategies (Chapter 3). In line with Participatory Action Research (PAR), it also promoted positive change in the local community as the process offered NGO representatives an opportunity to enhance their program evaluation skills, and helped them to improve the program using evaluation results and to be accountable to beneficiaries and donors. The evaluation design followed key features of sound CBR and empowerment evaluation identified in the literature review (Grandisson, Hébert, & Thibeault, 2014; Fetterman & Wandersman, 2005). Anonymous feedback boxes and a researcher's journal were used to generate lessons on best practices in CBR evaluation. Regarding ethical considerations, these were discussed in Chapter 2. The Office of Research Ethics from the University of Ottawa granted approval on December 16th 2011 (H10-11-06, Appendix B).

This chapter is written in an article format and is published in *Disability, CBR and Inclusive Development* (2014). The article title is 'Community-based rehabilitation program evaluations: Lessons learned in the field'. Plural possessive pronouns such as 'we' and 'our' are used to reflect the co-authors' contributions. This also follows the narrative style adopted in PAR (McNiff & Whitehead, 2009). The reader can find the consent forms and the discussion group guide used in this study in Appendices C and D respectively. The study findings enrich my understanding of some of the challenges and considerations associated with efforts to make CBR program evaluation empowering, inclusive, collaborative, enabling, respectful, sustainable and accurate. Further details on methodological decisions and their implications follow the article.

**4.1 Community-Based Rehabilitation Program Evaluations: Lessons Learned in the Field –
SECOND ARTICLE**

Marie Grandisson, Rachel Thibeault, & Michèle Hébert

School of Rehabilitation Sciences, University of Ottawa, Canada

Annie Templeton

Goedgedacht Trust, Malmesbury, South Africa

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Community-Based Rehabilitation Programme Evaluations: Lessons Learned in the Field

Marie Grandisson^{1*}, Rachel Thibeault¹, Michele Hébert¹, Annie Templeton²

1. School of Rehabilitation Sciences, University of Ottawa, Canada

2. Goedgedacht Trust, Malmesbury, South Africa

ABSTRACT

Purpose: *There is limited guidance available on the best ways to evaluate community-based rehabilitation (CBR) programmes. In this paper, we share lessons learned on suitable evaluation strategies for CBR through a South African programme evaluation.*

Method: *An empowerment evaluation of an early childhood development programme was conducted in April 2012. At the end of the field visit, parents, staff members and managers provided feedback anonymously about what they liked and disliked about the evaluation, and offered their suggestions. The principal investigator documented the evaluation process in a journal, recording the barriers and facilitators encountered, the participation of the 3 groups and the effectiveness of the different strategies used. The data analysis followed the principles of grounded theory.*

Results: *The main lessons learned about CBR programme evaluation are associated with strategies to: 1) foster active participation, 2) collect accurate and credible information, 3) build local capacity, and 4) foster sustainable partnerships. Time spent to promote a positive learning spirit and the use of participatory tools with all groups appeared critical to active engagement in evaluation activities. Sharing tools and experiences in context built more local capacity than was achieved through a formal workshop. The findings also highlight that a flexible model, multiple data collection methods, and involvement of all relevant stakeholders maximise the information gathered. Sensitivity to the impact of culture and to the reactions generated by the evaluation, along with ongoing clarifications with local partners, emerged as core components of sustainable partnerships.*

Conclusion: *CBR evaluators must use a variety of strategies to facilitate active engagement and build local capacity through the evaluation process. Many of*

* **Corresponding Author:** Marie Grandisson, Occupational Therapist, School of Rehabilitation Sciences, University of Ottawa, Canada.

the strategies identified relate to the way in which evaluators interact with local stakeholders to gain their trust, understand their perspectives, facilitate their contribution, and transfer knowledge. Further research is needed on how to conduct empowering CBR programme evaluations.

Key words: *empowerment evaluation, community-based rehabilitation, participation, partnerships, capacity building.*

INTRODUCTION

Community-based rehabilitation (CBR) is a strategy aimed at fostering community development that is inclusive of people with disabilities and is implemented by and for them (WHO, ILO, UNESCO, & IDDC, 2010). It is implemented in more than 90 countries. Yet, the evidence regarding whether and how it works, is insufficient and fragmented as few studies have looked at both implementation and outcomes, different outcome measures are used, and controlled trials are extremely rare (Finkenflugel et al, 2005). A systematic review indicates that CBR evaluations should: use more than one data collection method, combine qualitative and quantitative methodologies, be conducted in close collaboration with the local community in order to be empowering, and be followed by sharing findings and taking action (Grandisson et al, 2014). Others highlight that quantitative indicators to measure progress are vital (Wirz & Thomas, 2002). Thomas (2011) suggests that these should be derived from the CBR Matrix, which is at the heart of the most recent unifying document about this approach: the CBR Guidelines (WHO, ILO, UNESCO, & IDDC, 2010). Similarly, Grandisson and colleagues (2014) stress the importance of having a shared framework and suggest one, which blends the CBR Matrix (ILO, UNESCO, & WHO, 2004) and the Evaluation Hierarchy (Rossi et al, 2004).

Empowerment evaluations provide further direction on the best ways to evaluate programmes while empowering local communities (Fetterman & Wandersman, 2005), which is genuinely in line with the empowerment philosophy in CBR. This approach strives to achieve greater social justice and improve the lives of disadvantaged communities by “(1) providing programme stakeholders with tools for assessing the planning, implementation, and self-evaluation of their programme, and (2) mainstreaming evaluation as part of the planning and management of the programme/organisation” (Fetterman & Wandersman, 2005: p.28). It emphasises the need to enable stakeholder participation, including the most disadvantaged, through a collaborative, transparent and democratic

process. The evaluator acts as an analytical ally who builds trust by engaging in egalitarian relationships and creating a non-threatening learning climate. Empowerment evaluators build evaluation capacity and foster evaluative thinking by encouraging the use of the evaluation process and findings.

Objective

In this paper, we share lessons learned in one field study about evaluation strategies that we believe are relevant and applicable to CBR. First-person possessives and pronouns such as 'our' and 'we' are used in this manuscript to reflect our perspectives. This is congruent with the narrative style adopted in participatory action research (McNiff & Whitehead, 2009).

With a view to contributing to the discussion on best practices in CBR programme evaluations, our aim is not to present the outcomes of the evaluated programme or to draw comparisons with other evaluations, but to reflect on our process and share what we have learned.

The study was conducted through a partnership between the University of Ottawa and Goedgedacht, a non-governmental organisation (NGO) which offers inclusive community development services targeted at disadvantaged rural children and youth in the Western Cape, South Africa. Children of farm workers and their families are the main beneficiaries. They represent a marginalised population in which foetal alcohol spectrum disorder (FASD) is extremely common. Viljoen and colleagues (2005) estimated that 6.5% -7.4% of children in a Western Cape school had foetal alcohol syndrome (FAS), the most severe form of FASD. Among them, children from rural areas were seven times more likely to have FAS, with children of farm workers being particularly at risk.

Although FASD is not the most visible disability and is rarely targeted in CBR programmes, its most severe forms come with stunting, dysmorphology, developmental delays, learning disabilities and behavioural challenges, which in turn increase the risk of mental health problems, poor school performance and trouble with the law (Streisguth & Kanter, 1997). To alleviate social stigma, Goedgedacht's management chooses to avoid labels associated with disability and thus talks about inclusive community development rather than CBR. Their goal is to maximise the opportunities of rural children and youth for education, health and social life, working from a holistic approach to break the cycle of poverty and

marginalisation. Local graduates are encouraged to become community workers or volunteers for Goedgedacht. Although this may not be regarded as a pure CBR programme, it is guided by the CBR Matrix and endorses the CBR principles of participation, empowerment and inclusion of the most marginalised.

In congruence with participatory action research (PAR), empowerment evaluations and CBR, the NGO wished not only to evaluate its programmes but also to develop capacity to conduct its own evaluations independently (Hagey, 1997; Fetterman & Wandersman, 2005). To make this possible, evaluators from the University of Ottawa have agreed to support the organisation through cycles of evaluation and action over a period of approximately 10 years.

METHOD

Our evaluations of Goedgedacht's programmes were guided by the principles of empowerment evaluations and the characteristics of good CBR evaluations identified in a systematic review on this topic (Grandisson et al, 2014). The first field visit in 2011 engaged Canadian and South African partners in joint decisions on how to focus the evaluation. The second visit in April 2012 focussed on the evaluation of the early childhood development (ECD) programme offered to children up to 6 years of age, and forms the core of this paper. It is situated within the framework proposed by Grandisson and colleagues (2014) (Table 1). Ethical approval was obtained for this study. In this section, we describe the empowerment evaluation conducted and the methods used to learn about suitable evaluation strategies for CBR.

Empowerment Evaluation Conducted

Participants

We invited 3 groups to participate in the evaluation: 1) all the NGO's managers, 2) all the staff members involved in the ECD programme, and 3) parents of children attending the ECD programme. A convenient sampling strategy was used to identify the parents and they were recruited through joint home visits by the Canadian evaluators and a community member. After the purpose of the process was explained, free and informed consent was obtained from all participants verbally.

Table 1: CBR Programme Evaluation Framework including the South African evaluation (Adapted from Grandisson, Hébert & Thibeault, 2014)

		Relevance Fit between programme and community	Process How the programme operates	Outcomes Desirable and unintended	Costs Benefit and effectiveness
CBR Matrix	Education: Early childhood	<u>Needs:</u> Developmental delays are very present because of poor nutrition, poor stimulation and foetal alcohol spectrum disorders. No low-cost and accessible option was available in the area. <u>Activities:</u> The programme includes a low-cost early childhood centre for vulnerable children where they are fed and stimulated.	<u>Major facilitators:</u> Dedicated staff; material resources are adequate (games, building). <u>Major obstacles:</u> Sufficient training is not available for staff on children's development and FASD. Transportation of the children to the centre drains a large proportion of the financial resources.	<u>Readiness for school:</u> Parents, staff & managers believe children are a little more ready for school after attending the early childhood development centre. School readiness assessment shows small but significant positive differences. <u>Motor development:</u> Staff believe children reach development milestones, but parents and managers do not.	Not done at this point.

Data Collection Methods

To tap essential local knowledge, the Canadian partners asked the NGO managers for advice on suitable data collection methods that would maximise participation. Three data collection methods were used: 1) discussion groups with managers, staff members and parents, 2) key informant interviews with parents, with one staff member involved indirectly in the ECD programme and another in a position of authority over ECD staff, and 3) observations of programme activities at two different times using an observation grid. Parents were first interviewed individually in their homes, and then invited to a discussion group with other parents. The first meeting with all participants focussed on identifying the most desirable outcomes of the ECD programme, understanding its daily routine, as well as barriers and facilitators encountered. The second meeting was used to rate the programme performance in terms of the desirable outcomes common across all groups. Managers and evaluators also used the framework presented above to discuss the programme's logic model, and brainstormed to identify individual

assessments that could be used to measure change following participation in the ECD programme. To contribute to this discussion, evaluators used their clinical knowledge as occupational therapists, and explored assessments used with children with FASD and in early childhood CBR evaluations (for example, O'Toole, 1988; Adnams et al, 2007).

The discussion groups took place in a range of contexts. The sessions with managers and staff members were conducted in English during working hours, while the parents' meeting was held in the evening and conducted in Afrikaans with a translator present. Most of the activities with managers were conducted using a wall behind a table. With staff, the activities in the first session were done on a door. In the subsequent session with this group and with parents, large pieces of paper were placed on the floor, in the middle of a circle composed of participants and evaluators; everyone stood up occasionally to contribute.

In all the discussion groups with staff and parents, and in most of those with managers, we used participatory tools inspired by the Social Analysis Systems 2 (Chevalier & Buckles, 2008) to promote active engagement in evaluation activities. Staff members were invited to write the barriers and facilitators to their work on a dead tree (barriers) and a living tree (facilitators). Each staff member and parent placed a dot on a large visual scale to represent the extent to which the ECD programme helps children reach the desirable outcomes chosen, and shared a story to support their perception. With managers, flip charts and post-it notes were used to list ideas, organise thoughts, and facilitate discussions on the programme's logic model, the most important outcomes, and its main barriers and facilitators. Since members of this group all had tertiary education, on one occasion the evaluators asked each one to rate the ECD programme performance on a 4-point Likert scale.

Strategies to build Trust

Different strategies were used to build trust and facilitate democratic participation. One of these required that managers, staff members and parents be met in separate sessions and told that the information would be associated with a group rather than with an individual. The goal was to improve the programme, not to make judgments about individual performances. When staff members were reluctant to answer, they were invited to write on the sticky side of post-it notes so that no one could see who had written what. To help alleviate potential power differentials between the evaluators and participants, in some of the sessions the

evaluators sat on the floor next to the scale, while participants remained seated on chairs. Furthermore, they shared positive observations and understanding of challenges faced daily by staff.

Strategies to build Local Evaluation Capacity

A variety of strategies were used to build local evaluation capacity and promote a reflective culture. The South African and Canadian partners collaborated closely in preparing for the data collection and to ensure cultural relevance. Together we identified local personnel who would be trained in programme evaluation, including through a half-day workshop. The session included information about programme evaluation, case study examples, metaphors and interactive discussions. Local personnel experienced and learnt the participatory techniques used at the discussion groups. On one occasion, a local manager moderated an activity. When questioned about the techniques used, the evaluators introduced the team to an accessible guide to collaborative inquiry (Chevalier & Buckles, 2008). Similarly, while discussing the programme's logic model, the evaluators presented the CBR Guidelines (WHO, ILO, UNESCO, & IDDC, 2010).

Methods used to learn about Evaluation Strategies

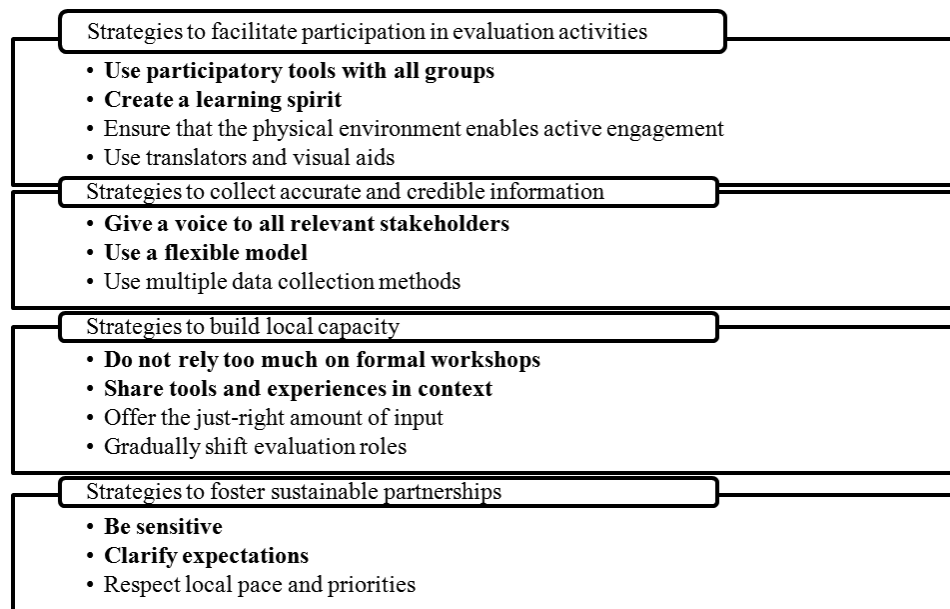
The principal investigator (MG) kept a journal of the evaluation process and recorded the barriers and facilitators encountered, the participation of the 3 groups, as well as her impressions about the effectiveness of the different strategies. At the end of the field visit, parents, staff members and managers gave written feedback anonymously on what they liked and disliked, along with their suggestions, and put their comments in small boxes. One staff member helped parents to write their comments. The managers also rated their general satisfaction on a 4-point Likert scale. Grounded theory was used to analyse the data, including open, axial and selective coding to develop propositions (Glaser & Strauss, 1967; Creswell, 2013). The Canadian partners led the analysis while one of Goedgedacht's managers confirmed that the themes generated represented her perceptions.

RESULTS

The 3 groups were well-satisfied with the evaluation process. All the 7 managers were very satisfied, and one said that he or she "absolutely loved the process"; staff members commented "You are welcome to come back", and parents said that they would welcome similar meetings. The main themes that emerged are

represented in Figure 1 and further described and supported in the text below with insights from the investigator's journal and the feedback received. They consist of lessons learned about strategies to facilitate participation in evaluation activities, to collect accurate and credible information, to build local capacity, and to foster sustainable partnerships. The elements highlighted in bold in the Figure represent strategies that were particularly critical in our experience.

Figure 1: Lessons Learned about Evaluation Strategies



Lessons Learned about Strategies to Facilitate Participation in Evaluation Activities

Use participatory tools with all groups

Indications from the feedback received and the evaluator's journal were that participatory tools effectively fostered the active engagement of parents, staff and managers. Staff members said *"We liked everything that you did with us"*. Parents readily participated in the proposed activity and shared their personal stories. They suggested that meetings with programme representatives should always follow such a format. Managers were also active and engaged in reflecting on the programme when participatory exercises were used. In contrast, when a traditional format was chosen, one participant was unable to answer the questions with a Likert scale and the whole group appeared tense.

Create a learning spirit

There were indications that it is necessary to create a learning spirit where everyone reflects on the programme to shape its future, rather than making judgements on individual performances. Managers appreciated the *“learning spirit that you brought in the process”*. Strategies to ensure anonymity appeared to be effective with staff members. As soon as they realised that by writing on the sticky side of post-it notes they could never be identified, they enthusiastically wrote down ideas about the barriers and facilitators to their work, and asked for more post-it notes. They commented: *“They did not judge us”* and *“We could talk freely”*.

Ensure that the physical environment enables active engagement

Participation varied significantly according to the physical environment. There was more engagement by staff and parents when the activities took place on the floor; they all stood up excitedly to add their dots or post-it notes, and shared stories generously. The setting used with managers (i.e. activities on the wall behind the table) proved less than optimal, as it curtailed participation; the tendency was to ask the evaluator to put up their post-it notes.

Use translators and visual aids

Among the strategies to facilitate participation, another theme relates to the importance of using translators and visual aids to reduce language barriers. Reflections in the investigator’s journal highlighted this. The presence of a translator during the parents’ meeting allowed them to share their ideas comfortably, and many even forgot to wait for English translations. In addition, the use of participatory visual activities reduced the linguistic demands for all, which we feel enhanced participation.

Lessons Learned about Strategies to Collect Accurate and Credible Information

Give a voice to all relevant stakeholders

This turned out to be extremely important as it helped gather complementary material. Parents, staff and managers alike could express their opinions within a safe space conducive to sharing in greater detail. Naturally, this multi-stakeholder consultation yielded some divergent data and the diversity of views collected contributed important nuances to the final interpretation of the findings. For

example, the perceptions on service accessibility conflicted at times: the managers considered their programme inclusive whereas one parent indicated that her child with Down syndrome remained at home. Ultimately, this collaborative process helped produce evaluation findings considered credible and valuable by all. Parents' self-esteem and sense of belonging was bolstered by being consulted; they stated repeatedly how privileged they felt to be participating in the discussions. The local translator felt that our initial visit to their houses had contributed to the way they shared very openly in the discussion group.

Use a flexible model

Using a model provided our entire team with a shared language and understanding of the organisation's goals and target populations. For example, some members were reluctant to use the phrase 'children with disabilities' and preferred using 'disadvantaged children'. The collective designing of the ECD programme logic model helped managers to reflect on their priorities, objectives and means, and generated much information. One manager stated that this was a good *"opportunity for us as a team to think together, clarify concepts, identify focus areas indicators"*, while another said it helped in *"making implicit explicit"*.

Flexibility is also essential. In our case, all 3 groups identified children's confidence as a priority indicator of change despite its absence from the desirable outcomes of ECD in the CBR Guidelines. Furthermore, although the South African partners agreed to start the evaluation with analyses of relevance, move on to process and outcomes, and conduct cost analyses later on as suggested in the framework, they also wanted age ranges to appear in the model to facilitate programme replication.

Use multiple data collection methods

We also realised the importance of triangulating the information using multiple methods. Here, on-site observations significantly added to individual and group discussions, since they enabled us to capture the challenges associated with FASD more accurately. Another point is that we should not rely only on quantitative ratings, as all parents placed their post-it notes on the highest possible point of the scale when evaluating the programme. Nonetheless, stories shared to support their ratings were congruent with their evaluation. Individual assessments of children would have offered complementary data to meet donors' requirements, but the investigator's journal reflects that the locally available school readiness

scales and developmental assessment tools were too complex or dependent on too many external resources to be of sustainable use for an organisation that wishes to develop capacity to conduct evaluations independently.

Lessons Learned about Strategies to build Local Capacity

The managers valued the capacity building efforts; they appreciated *“how you used the process for our own education – informing us of research, methods”*.

Do not rely too much on formal workshops

Building evaluation capacity through formal methods such as a workshop sessions was challenging. Even though we had confirmed our partners' interest in the session, we realised that the personnel could devote little time to it and that participants were more interested in sharing their thoughts about the programme than learning about evaluation. The evaluators felt that the participants did not gain much applicable knowledge during the session.

Share tools and experiences in context

Building capacity by sharing useful tools and experiences as needs or difficulties arose appeared much more effective. On that point, the South African managers said that they greatly appreciated the *“sharing”, “the way you bring support from previous research and experience”, “the information on the rest of the world”* and the *“tools shared”*. The evaluators noted that they appeared particularly enthusiastic when tools such as the CBR Guidelines (WHO, ILO, UNESCO, & IDDC, 2010), early development checklists, participatory tools (Chevalier & Buckles, 2008), educational videos and drop box were presented, and their relevance to the programme discussed.

Offer the just-right amount of input

Another theme that emerged is the need for evaluators to be analytical allies to programme stakeholders by offering the just-right amount of input. Managers mentioned that it was *“so good to be challenged”* and that they liked *“how you managed the discussions”, “reframed concepts”* and *“focussed on designing the general process”*. The Canadian partners influenced the process at some stages by drawing attention to discrepancies pertaining to intended or unintended outcomes, and about differences between what the programme aims to be doing and is actually doing. Reflections in the investigator's journal highlight the fact that input must

be offered in moderation, without reframing concepts too often, which could decrease people's confidence and inhibit them from sharing relevant information.

Gradually shift evaluation roles

The last strategy used to strengthen local capacity, which appeared to be effective, is to gradually shift evaluation roles to identified local personnel who are expected to take responsibility in the future. The way we collaborated in preparation for data collection allowed people to become familiar with evaluation planning and data collection methods. The translator for the discussion group and the manager who led part of one session gained experience and confidence to moderate such sessions, and fulfilled their roles with professionalism.

Lessons Learned about Strategies to foster Sustainable Partnerships

Be sensitive

The investigator's journal contained many reflections about the importance of being sensitive to the impact of cultural beliefs and to the reactions generated by the evaluation. In one instance, the Canadians would have more readily labelled the children living with FASD as children with disability. They were also inclined to deplore the local reticence to obtain a diagnosis, feeling it could jeopardise the eventual development of necessary services. The South African partners however, saw in an official diagnosis a detrimental label that would only lead to more stigmatisation. We were sensitive to the fact that we held different beliefs, and decided to put this issue into perspective so that each scenario's advantages and disadvantages could in time be discussed with consideration.

Similarly, when a formal activity was conducted to rate the centre's performance, the group appeared tense. We realised that this part of the evaluation could be threatening and that the format chosen was not appropriate. The tension disappeared when the Canadian partners adjusted their methods to include more participatory activities and offered options to their South African partners as to how they wanted to proceed. Managers commented that they liked the evaluators' "*sensitivity*".

Clarify expectations

This experience draws attention to the importance of clarifying each other's expectations, especially when evaluators come from abroad. The Canadian

partners did not realise the extent to which findings were used quickly until one manager asked to *“get the evaluation report earlier to do better preparation before the next round of evaluation”*. Another example comes from the suggestion that *“April is a very busy time: can we please make it around February (next time)?”* The South African partners showed that they wanted to be more actively engaged and suggested reflecting on ways to maintain *“more clarity and communication between us and you during the year about the thinking process”*. This certainly highlights the importance of getting to know our partners and letting each one determine their preferred level of involvement.

Respect local pace and priorities

The last theme that emerged to foster sustainable partnerships is to respect local pace and priorities. On that subject, one manager mentioned that he liked the *“way you gave participants time to formulate and express ideas in order not just to stay on (a) predetermined path but to draw in complex issues in a non-threatening manner”*. Another appreciated *“the pace at which the evaluation is taking place”*. On some occasions the evaluators were worried that not all evaluation objectives would be met, since discussions sometimes appeared to be straying far from the evaluation focus. The partners decided to adjust the objectives to take into account immediate local priorities: we kept the focus on evaluating the ECD activities, but priority elements associated with the entire programme were discussed, such as expansion in other communities, as someone suggested that it was *“the elephant in the room”*. The feedback received indicates that this was appreciated.

DISCUSSION

This study provides insights into strategies applicable to CBR evaluations. The golden thread connecting our findings relates to how evaluators interact with local stakeholders to gain their trust, understand their perspectives, facilitate their contribution, and build local capacity. For example, the non-threatening learning spirit that was created proved absolutely essential to gain trust and enable people to participate actively in evaluation activities. This reinforces the need for evaluators to engage in non-judgmental relationships and position themselves as analytical allies for programme stakeholders (Fetterman & Wandersman, 2005; Chevalier & Buckles, 2013).

Sensitivity towards each other's perspectives and reactions emerged as critical in the evaluation of the South African programme. This highlights how important it

is for evaluators to pay attention to verbal and non-verbal cues in order to gain a good understanding of their partners' beliefs, realities and communication styles, and to adjust their terminology, methodology and interpretations accordingly (Chevalier & Buckles, 2013). This is especially challenging when engaged in participatory research with people from different cultures. The issue of what is perceived as a disability may often come up in CBR evaluations, as was the case in this study. To overcome potential pitfalls, the authors suggest that partners must commit to ongoing self-critique of their own biases, and recognise the legitimacy of other perspectives (Gray & McPherson, 2005; Ross, 2010). Hence, CBR evaluators must be conscious of their own perceptions of disability and reactions, and engage in balanced discussions to understand their partners' vision.

All the groups in this study appreciated the efforts to give a voice to all and to facilitate the contribution of people with different literacy levels through the use of participatory tools. This also brought important nuances to final interpretations. This is in harmony with CBR values of inclusion and participation, while being congruent with empowerment evaluations and PAR (Fetterman & Wandersman, 2005; WHO, ILO, UNESCO, & IDDC, 2010; Chevalier & Buckles, 2013). As expected, the strong visual component of the participatory tools helped to reduce language and literacy barriers. Nonetheless, the fact that they were also very effective with tertiary-educated individuals supports a more generalised use of these highly interactive tools in CBR evaluations.

On another note, it was difficult for us to identify a suitable tool to gather longitudinal information on children's progress that would not require external resources. On that subject, Lukersmith and colleagues (2013) highlighted the need for a CBR monitoring and evaluation tool, but stressed that it must be adaptable and that the resource implications must be considered. Similarly, although the framework used facilitated reflections on the programme, our experience suggests that a one-size-fits-all framework would not be appropriate for CBR. That might partly explain why there is still no consensus on which one should be used (Grandisson et al, 2014).

Capacity building efforts which are at the heart of empowerment evaluations (Fetterman & Wandersman, 2005) were greatly appreciated by local stakeholders, and provide support for the use of this approach in CBR evaluations. However, our findings emphasise that a variety of capacity building strategies should be used. Informal strategies appeared to work best in this study and required the

evaluator to seize opportunities to transfer knowledge in context and delegate roles gradually. Fetterman and Wandersman (2005) propose that fostering evaluative thinking with cycles of reflection and action can empower local stakeholders to make optimal use of evaluations. This was clearly demonstrated as the South African managers liked to be guided in their reflections about the programme and were eager to use the results of the evaluation to prepare for the next round.

The lessons learned are specific to the partnership between the University of Ottawa and Goedgedacht, and are focussed on one of the field visits conducted to empower the NGO to evaluate its programmes. We are aware that stakeholders' participation can vary greatly from one culture and one programme to another. Although we attempted to create conditions conducive to feedback, some people may have been intimidated. More research and best practice guidelines representing consensus of experts would provide further guidance on how to conduct empowering CBR evaluations.

CONCLUSION

We hope that the lessons learned about CBR evaluation strategies can be useful to others. Our experience revealed the importance of creating a non-threatening learning spirit and providing support for the use of participatory tools with all groups during CBR evaluations. Being sensitive to our partners' beliefs about disability and inclusion as well as their reactions to the evaluation, emerged as a crucial issue. This study also emphasised the need for a variety of formal and informal strategies to develop local evaluation capacity. More research is needed to clearly define the key ingredients for good CBR evaluations, to look into strategies to build local evaluation capacity, develop a flexible monitoring and evaluation tool for CBR, and attempt to reach consensus on a flexible framework in which to position CBR evaluation findings.

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4.2 Why Did I Make these Methodological Decisions?

In this section, I further explain the methodological decisions made in the field study to clarify how features from the initial best practice model (Chapter 3) and from my PAR lens influenced them. I discuss: 1) my reasons for favouring perspectives of parents, staff members, and managers, 2) participants' recruitment and participation, 3) consent documentation, and 4) my rationale for using a journal and suggestion boxes to evaluate the process.

4.2.1 Reasons for favouring perspectives of parents, staff members and managers.

Congruent with indications found in the literature review (Fetterman & Wandersman, 2005; Mertens, 2009; Patton, 2012), the three most affected groups were asked to contribute to the South African program evaluation. Parents acted as proxies since children affected by the ECD program are six years of age or younger. Staff members provided a clear and realistic picture of the program and its challenges. Managers offered a holistic view of the program aim, its links with other services, donors' expectations and other organizational considerations. Although adding partner organizations' perspectives could have been relevant, resources and time available made this unmanageable. To compensate for this, evaluators asked managers to consider these other actors' perspectives at different points (e.g. reminded to think of donors' preferred outcomes). This strategy followed Bamberger and colleagues' (2012) suggestions to address budget and time constraints.

4.2.2 Participant's recruitment and participation. Observations of power differentials and discussions with local representatives helped determine that it would be most beneficial to divide the participants into three homogeneous groups for the ECD evaluation: parents, staff members, and managers. This closely follows my PAR perspective as questions of power were explicitly addressed to ensure that the least powerful also had a real voice in the process (Chevalier & Buckles, 2013b). Parents were recruited through a purposive sampling strategy.

Staff members identified parents of children of different ages who held a range of views about the program. Community knowledge was used to identify suitable recruitment strategies (Fetterman & Wandersman, 2005). Parents were then recruited through joint home visits by the Canadian evaluators and a community member. If they consented, they were immediately interviewed in their homes to collect a first narrative and build trust by providing individual attention and ensuring they felt comfortable sharing their opinions. This is in line with democratic participation (Fetterman & Wandersman, 2005). Evaluators then invited parents to attend a group session to further explore their views and share their experiences with others. All staff members involved in the ECD program on a daily basis were invited to take part in two discussion groups. The local managers first informed them of a potential meeting with the evaluators. To reduce apprehensions and build trust, the evaluators then clarified the purpose of the process and how their viewpoint was valued and would be reported as a group. Regarding managers, their recruitment was facilitated by the fact that they had requested help from my supervisor (RT) to evaluate their program. The initial field visit in February 2011 also familiarized them with the evaluation process and built trust in the evaluators. Again, in line with empowerment evaluation (Fetterman & Wandersman, 2005), the two local co-directors of the overall Path Out of Poverty (POP) program decided who was going to be asked to be part of the managers' group in the ECD evaluation. In addition to themselves, they chose to ask the staff capacity building leader and four local consultants currently supporting ECD staff (i.e. a physiotherapist, two early childhood specialists, and an education specialist) to participate. The ECD leader was also identified as one of the managers of the program. Nonetheless, following the co-directors' recommendation, she was interviewed separately to ensure that she would feel comfortable sharing her opinions freely.

4.2.3 Consent documentation. After explaining the purpose of the process, evaluators obtained and documented free and informed verbal consent from all participants. Although we initially intended to ask for written consent, it was deemed culturally inappropriate by *Goedgedacht*'s representatives as it would have intimidated some participants and stigmatized those who were illiterate. Adjusting our methods using community knowledge is also congruent with empowerment evaluation (Fetterman & Wandersman, 2005). The evaluators also clarified with all parents, staff members, and managers that their participation was entirely voluntary and could be withdrawn at any time without any negative consequence.

4.2.4 Rationale for using a journal and suggestion boxes. Using a researcher's journal and suggestion boxes follows PAR philosophy, as researchers' and participants' experiential knowledge are valued (Herr & Anderson, 2005; McNiff & Whitehead, 2009). In the journal, the author reflected on the evaluation process and took detailed notes on the barriers and facilitators encountered, the participants' responses the different strategies used to facilitate participation in evaluation activities and build local evaluative capacity. Because the fieldwork was very intensive over 2 weeks, she recorded her thoughts in point form mostly, which may explain that we sometimes paraphrased segments from the journal instead of including quotes in the article.

Suggestion boxes were also used to enable all participants to share their thoughts on the process. This choice was made to ensure all would share their positive and negative comments freely. This is aligned with inclusion and democratic participation (Fetterman & Wandersman, 2005) since everyone has a voice and the experience of all participants, including the researchers', is valued. On the one hand, the use of the suggestion boxes was mostly positive; it enabled participants to provide feedback quickly, anonymously and freely. Some comments would probably never have been mentioned otherwise (e.g. asking to get the evaluation report quickly). On the other hand, negative consequences of this strategy were that most comments

only consisted of a few words and regarded the general process rather than specific strategies used. In addition, we did not include excerpts from discussion groups with participants as evidence for the lessons learned as we prioritized the gathering of anonymous feedback on the evaluation process and chose not to use audio-recording in the sessions to ensure that all would feel comfortable sharing their thoughts. To alleviate the impact of these limitations, and in harmony with the value given to community knowledge (Fetterman & Wandersman, 2005), a local partner reviewed our analyses to validate our interpretations. Similarly, Tsey and colleagues (2004) had also used labelled feedback boxes as part of their PAR process with a men's self-help group in an Aboriginal community. The authors indicated that it stimulated ongoing reflection and problem solving by all those involved.

4.3 Conclusion

In this fourth chapter, I described the piloting of my initial model for best practices in CBR evaluation and the lessons learned. The findings highlight the importance of developing strong partnerships with program stakeholders and provide directions on how to create and sustain them. Engaging in egalitarian and non-judgemental relationships, clarifying each other's expectations, being sensitive to the impact of cultural differences, and respecting local pace were key. Furthermore, our experience reinforces the goodness of fit between empowerment evaluation (Fetterman & Wandersman, 2005) and CBR; program stakeholders widely appreciated capacity building efforts and clearly developed their evaluative thinking. Nonetheless, more research on how to carry empowering CBR evaluation is needed. The strategies identified in this study highlighted the need for evaluators to be creative. They include: not relying too much on formal workshop sessions, gradually delegating evaluation roles to local personnel, sharing tools gradually as specific needs are identified by local partners, and offering the just-right amount of input to foster reflective thinking and stimulate program stakeholders to use gathered evidence

for decision-making. In addition, this field study indicates that CBR evaluators should use several strategies to maximize participation in evaluation activities and be ready to adjust as the evaluation evolves. In this instance, participatory tools and techniques, such as those suggested by Chevalier & Buckles (2013b), were highly effective to facilitate engagement of all groups, regardless of their literacy level. Triangulating data from multiple sources and methods proved to be key since stakeholders held diverging perspectives on the challenges associated with FASD. As for data collection tools, we had difficulty identifying a suitable tool to gather objective longitudinal information about each child's development or school readiness. Thus, we decided to develop a new one specific to the local community profile and evaluation context, even though we believed that having a set a flexible CBR evaluation tools from which to draw could facilitate CBR evaluations and cross-comparisons. This supports Lukersmith and colleagues' (2013) suggestion that developing flexible CBR monitoring and evaluation tools for use across programs could be beneficial. In regard to the use of a common framework across all CBR program evaluations, our experience corroborates Chen's (2005) theory as the framework not only fostered evaluative thinking, but also helped identify gaps between program aims and achievements. Yet, it succeeded largely because of its flexible nature. Finally, this study provided real-life applications for best practice guidelines in CBR evaluation. In the subsequent chapter, I present an experts consultation aimed at generating consensus about best evaluative practices in CBR among a panel of experienced representatives and leaders from the CBR community.

Chapter 5: Community-Based Rehabilitation Program Evaluation: Generating Consensus

Limited guidance is available to those engaging in community-based rehabilitation (CBR) program evaluation. The systematic review conducted enabled the author to propose potential features of sound CBR evaluations and highlighted diverging opinions in regard to suitable evaluations for CBR (Grandisson, Hébert, & Thibeault, 2014). The *CBR Guidelines* (WHO, UNESCO, ILO, & IDDC, 2010) stress the need to evaluate CBR programs but provide rather limited directions as to how it should be done. To fill this gap, the World Health Organization (WHO) launched a call for proposals for a CBR manual on monitoring and evaluation in the summer of 2014. Such manual typically includes practice guidelines, which represent systematically developed statements to guide evaluative decisions and foster reflective practice (AGREE Next Step Consortium, 2009; Yarbrough, Shula, Hopson, & Caruthers, 2011). The call for proposals requested that the manual must be grounded in processes designed to reach consensus on best evaluative practices in CBR. This is exactly what the third and last phase of my doctoral thesis accomplished.

This chapter introduces the Delphi study that was conducted to generate consensus on best evaluative practices in CBR. This experts consultation built upon the previous phases of this doctoral thesis as a summary of the findings from the systematic review and the field study was provided to participants, and insights from the first two phases were used to prepare the questionnaire for the first experts consultation round. A total of two rounds were completed with 42 experts in CBR coming from a wide range of vantage points, and with knowledge and experience relevant to program evaluation. The questionnaires for both rounds covered sociodemographic characteristics, key features of best practices related to CBR evaluation processes and methods, and potential frameworks. Round 1 focused on identifying the most essential features of sound CBR evaluation, while Round 2 was mostly designed to validate the

recommendations generated in Round 1 and investigate issues that did not obtain consensus in the first round.

This chapter is written in an article format. The manuscript is published in *Disability and Rehabilitation* and adheres to its editing policies. The manuscript is presented in 5.1 and followed in 5.2 by additional details on the results of the experts consultation: these include panellists' comments on the criteria for sound CBR evaluation processes, their preferred data collection methods, their strategies to foster a good community-method fit, and their perceptions on the pros and cons of the potential shared frameworks for CBR evaluation proposed. Invitations to participate, questionnaires used and summary of findings for each round are available in Appendices E, F, G, H, I, and J of this thesis.

5.1 Expert Consensus on Best Evaluative Practices in Community-Based Rehabilitation - THIRD ARTICLE

Marie Grandisson, Rachel Thibeault, & Michèle Hébert

School of Rehabilitation Sciences, University of Ottawa, Canada

Debra Cameron

Department of Occupational Science and Occupational Therapy, University of Toronto, Canada

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RESEARCH PAPER

Expert consensus on best evaluative practices in community-based rehabilitation

Marie Grandisson¹, Rachel Thibeault¹, Michèle Hébert¹, and Debra Cameron²

¹School of Rehabilitation Sciences, University of Ottawa, Ottawa, Ontario, Canada and ²Department of Occupational Science and Occupational Therapy, University of Toronto, Toronto, Ontario, Canada

Abstract

Purpose: The objective of this study was to generate expert consensus on best evaluative practices for community-based rehabilitation (CBR). This consensus includes key features of the evaluation process and methods, and discussion of whether a shared framework should be used to report findings and, if so, which framework should play this role. **Method:** A Delphi study with two predefined rounds was conducted. Experts in CBR from a wide range of geographical areas and disciplinary backgrounds were recruited to complete the questionnaires. Both quantitative and qualitative analyses were performed to generate the recommendations for best practices in CBR evaluation. **Results:** A panel of 42 experts reached consensus on 13 recommendations for best evaluative practices in CBR. In regard to the critical qualities of sound CBR evaluation processes, panellists emphasized that these processes should be inclusive, participatory, empowering and respectful of local cultures and languages. The group agreed that evaluators should consider the use of mixed methods and participatory tools, and should combine indicators from a universal list of CBR indicators with locally generated ones. The group also agreed that a common framework should guide CBR evaluations, and that this framework should be a flexible combination between the CBR Matrix and the CBR Principles. **Conclusions:** An expert panel reached consensus on key features of best evaluative practices in CBR. Knowledge transfer initiatives are now required to develop guidelines, tools and training opportunities to facilitate CBR program evaluations.

Keywords

Community-based rehabilitation, evaluation, expert consensus, framework, process, program evaluation

History

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► Implications for Rehabilitation

- CBR evaluation processes should strive to be inclusive, participatory, empowering and respectful of local cultures and languages.
- CBR evaluators should strongly consider using mixed methods, participatory tools, a combination of indicators generated with the local community and with others from a bank of CBR indicators.
- CBR evaluations should be situated within a shared, but flexible, framework. This shared framework could combine the CBR Matrix and the CBR Principles.

Introduction

Community-based rehabilitation (CBR) is an inclusive community development strategy that aims to maximize opportunities for people with disabilities and their families in the areas of health, education, livelihood, social life and full-fledged community participation [1,2]. These aspirations are usually accomplished by facilitating access to mainstream services and delivering community-based disability-specific services. CBR programs are now implemented in more than 90 countries, primarily in low- and middle-income economies. Despite this, the evidence for CBR

effectiveness is described as weak and fragmented [3]. This does not necessarily mean that CBR does not foster positive change; rather, the authors believe that more attention needs to be given to the evaluation of CBR initiatives.

The debate on how CBR evaluation should be carried is very active. Cornielje et al. [4] highlighted the suitability of mixed methods for CBR, the importance of baseline data and the necessity to generate indicators for the specific needs of the program targeted. Finkenflugel et al. [5] recommended the use of indicators derived from classification, models while Thomas [6] proposed that the CBR Matrix [1] could play this role. Chung et al. [7] suggested another framework for CBR evaluations, specific to Chinese communities. Regarding data collection tools, Adeoye et al. [8] developed one in Uganda and suggested that their process could be replicated to produce locally relevant tools.

Lukersmith et al. [9] proposed key principles that should be considered when selecting a tool. Finally, Grandisson et al. [10] and Grandisson et al. [11] highlighted the need for a shared framework, an empowering approach to evaluation and the use of participatory tools with all involved. A systematic review on how to conduct CBR program evaluations offers further details on areas of agreement and disagreement between authors [10]. Yet, as long as there is no consensus on what should be considered best practices in CBR evaluation, insufficient directions will be available to those wishing to conduct rigorous CBR program evaluations aligned with CBR's core principles.

Objective

The objective of the first author's doctoral thesis was to develop guidelines on best practices in CBR program evaluation. The first step was a systematic review on how to conduct CBR evaluations [10]. The second step was a field study in which a South African program for children with foetal alcohol spectrum disorders was evaluated. The process was appraised to produce knowledge on suitable strategies for CBR evaluations [11]. The study reported here represents the third step of this doctoral research process. Its objective was to generate expert consensus about best evaluative practices in CBR. This consensus includes the key features of evaluation processes and methods, whether a shared framework to situate CBR evaluations would be beneficial and, if so, which framework should be used.

Methods

A Delphi study [12,13] was conducted to generate consensus on best evaluative practices in CBR. It is a strong, yet feasible way of building collective agreement when experts come from geographically diverse areas. In classic Delphi designs, a series of questionnaires are sent by mail to a group of informed individuals about a particular topic in an effort to reach consensus [14]. Summaries of group opinions are provided to panellists between consultation rounds. While a Delphi study has as many rounds as required to reach consensus or obtain stability of responses, two or three rounds are most often preferred [12]. A Delphi study with two predefined rounds was performed in 2013–2014. A mixed methods approach was chosen to seek experts' opinions, obtain a good understanding of their rationale and leave space for their suggestions.

Data collection methods

Questionnaires were used in both rounds of this consultation in order to seek experts' opinions on best evaluative practices in CBR. These are available upon request to the first author. Round 1 questionnaire was developed using the findings from the previous phases of this study. It consisted of 21 questions, including multiple-choice, Likert scales, ranking, and open-ended questions on best practices in CBR program evaluation. It was divided into four sections: sociodemographic characteristics of the respondents, evaluation process, data collection methods and frameworks. The questionnaire for the second round contained 20 questions, including closed- (e.g. Likert scale and yes or no) as well as open-ended questions. It was divided into three sections: (1) comments on Round 1 findings, (2) editing suggestions on the recommendations that reached consensus after Round 1 and (3) opinions on new recommendations based on panellists' suggestions and on elements that did not reach consensus in Round 1. All authors reviewed both questionnaires. They were then pilot tested with five professionals who were not part of the panel, but who were knowledgeable about CBR and evaluation of community development initiatives. The consultation was mostly conducted

online using FluidSurveys (www.fluidsveys.com) as a platform for the questionnaires. In an effort to increase response rate, hard copies of the questionnaires were also sent to all participants in Round 1. In Round 2, only those who used the hard copy in the first round or who requested one received a hard copy.

Panellists recruitment

Purposive sampling was used to assemble a heterogeneous panel of CBR experts. The main inclusion criterion was to be knowledgeable about CBR. Efforts were made to recruit panellists from all geographical areas of the world, who played different roles in CBR, including academics, CBR managers and employees of organizations involved in CBR. The recruitment focussed on individuals with some experience or knowledge related to program evaluation. Yet, this was not an exclusion criterion since the priority was to gather a panel of informed individuals and leaders of the CBR community from all around the world. The two exclusion criteria were not being able to respond to a questionnaire available in English and never having been in direct contact with CBR programs. Participants had the opportunity to write their answers in English, French or Spanish.

The recruitment procedure for Round 1 (May 2013) and Round 2 (June 2014) is presented in Table 1. Thirty-five potential panellists were initially identified because they wrote or presented at conferences about CBR program evaluations, participated in an international working group on this topic or were known through personal contacts of the first two authors. Snowball sampling upon initial contact was also used. The CBR experts contacted were asked to identify people working in the field in CBR who would also be interested by this study. For each round, two reminders were sent by email to those who had not responded, congruent with Keeney et al. [14] recommendations. No incentive was provided to panellists, except for the mention of their name in the acknowledgements of the present article. They were told that they were free to participate or not. For both rounds, consent was implied by their completion of the questionnaire either electronically or by hard copy.

Data analysis

There is no universal proportion of agreement defined as consensus for Delphi studies. Authors have recommended proportions ranging from 51% to 80% [12,15]. In this study,

Table 1. Delphi procedure used in this study.

1. Personalized prenotification email sent to all potential panellists two weeks prior to the consultation, snowball sampling upon initial contact
2. Invitation to complete Round 1 sent to all potential panellists with summary of findings from previous phases of this doctoral thesis and link to online questionnaire
3. Reminder sent to those who had not responded after two weeks
4. Personalized reminder sent to those who had not responded after four weeks
5. Analyses of Round 1
6. Personalized prenotification email sent to all those who had completed Round 1 two weeks prior to Round 2 with summary of Round 1 findings
7. Invitation to comment on Round 1 findings and complete Round 2 with a link to the online questionnaire sent to all those who completed Round 1
8. Reminders sent to those who had not responded after two weeks
9. Personalized reminder sent to those who had not responded after four weeks
10. Analyses of Round 2
11. Summary of Round 2 findings sent to all panellists
12. Final report

it was decided beforehand that consensus would be reached when 75% or more agreed. A high cut-off point was chosen to ensure that the recommendations would be acceptable to the CBR community. This is also consistent with Diamond et al.' findings [16] from a systematic review of 98 Delphi studies, where the authors found a median threshold for consensus of 75%. Quantitative analyses used IBM SPSS data analysis software [computer program, version 21] (New York, USA) and focused on descriptive statistics including central tendencies, frequencies and proportions. Comparisons of proportions using Fisher Exact Tests were also performed to explore whether respondents with certain sociodemographic characteristics had different opinions regarding the most important criteria for sound CBR evaluation, preferred methodologies, and choice of one common framework to support CBR evaluation over another. For each open-ended question, qualitative analyses were conducted on Hyperresearch software [computer program, version 3.5.2] through inductive coding with constant comparative analyses [17,18]. All subcategories were retained regardless of frequency. The first author conducted the analyses, and all other authors then verified whether the themes generated represented the key quotes included.

Results

The findings are presented in four sections: panellists' characteristics are followed by their opinions regarding sound CBR evaluation processes, methods and potential frameworks in which results could be situated.

Panellists' characteristics

A total of 61 individuals were invited to participate in this study. Two of them were excluded because they were unable to complete the questionnaire in English. Seventy-one percent (42/59) of all eligible individuals invited completed Round 1 and were contacted to participate in Round 2. Eighty-six percent (36/42) of them also completed the second round. The panel is therefore composed of 42 individuals who are highly knowledgeable about CBR program evaluation and who completed at least one round. Reasons given for not completing the questionnaires included holiday, sickness, maternity leave and lack of time. Comparisons of proportions indicate that the characteristics of those who were unable to complete Round 2 do not differ significantly from the rest of the panel in terms of income-level of their country of residence, role in CBR, experience or disability status. Almost all responded online. Only three used the hard copy in Round 1 and

one in Round 2. More details about recruitment procedures and responses are shown in Figure 1.

Panellists came from a wide range of viewpoints: 12 were non-governmental organizations' (NGOs) employees, 12 were researchers, 5 were coordinators, 3 were consultants, 2 were United Nations organizations' employees, 2 were involved in university-based centres, 2 were funders and consultants, 1 was a program manager, 1 was a community worker, 1 was a donor and 1 had worked for both United Nations organizations and NGOs. All had been in direct contact with CBR programs and 37/42 had been involved in a CBR program evaluation before Round 1. They were highly experienced, with 33/42 reporting 10 years of experience or more in CBR and 18/42 with 10 years or more in program evaluation. Five individuals reported living with a disability. Ten stated working in the field with local CBR programs five months or more each year.

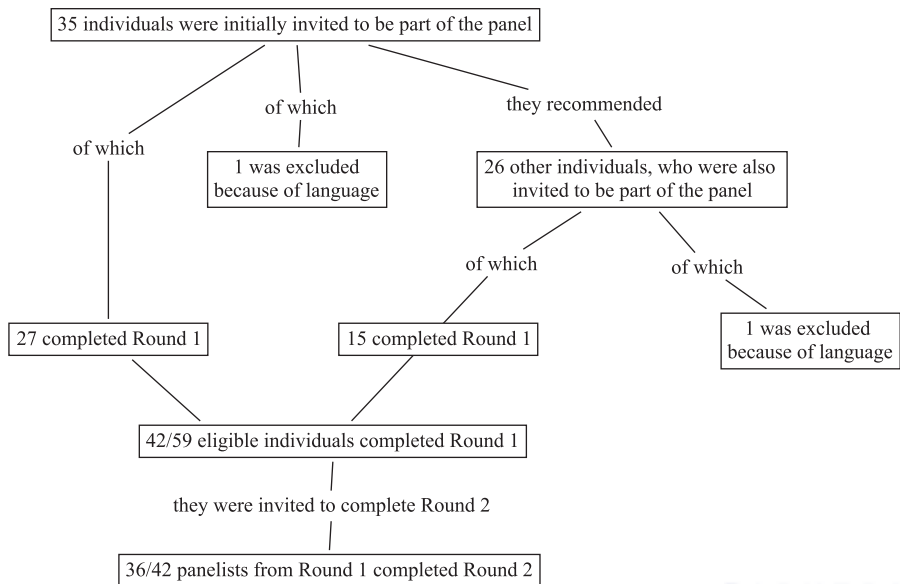
Panellists from all around the world were recruited: Table 2 presents where they live and where they have been involved in CBR programs. More than half (25/42) live in high-income countries, 14 live in middle-income, and 3 live in low-income countries.

At the beginning of Round 2, participants provided comments on the panel composition after reviewing its characteristics and the names of all those involved. Overall, most highlighted that the panel represented a well-balanced range of valuable perspectives in relation to geographical spread, roles in CBR and gender. In regard to panellists' credibility, one stated: "The people whom I know on the panel are all people I have a lot of respect for because of their previous contributions to strengthening CBR." Nonetheless, two indicated that in an ideal scenario, there would have been more representatives from some regions and who had a disability.

Table 2. Continents in which panellists live and have been involved in CBR programs.

	Where they live n (%)	Where they have been involved in CBR n (%)
Africa	3 (7%)	17 (40%)
Asia	8 (19%)	33 (79%)
Australia	5 (11%)	4 (10%)
Europe	13 (31%)	4 (10%)
North America	8 (19%)	2 (5%)
South America	5 (11%)	16 (38%)

Figure 1. Flow chart of invitations and responses for both rounds.



Panellists' opinions on the features of sound CBR evaluation processes

The results concerning sound CBR evaluation processes include the most important criteria, the steps involved and strategies to alleviate linguistic differences. All Round 1 results concerning evaluation processes are presented first, and followed by a table summarizing Round 2 results.

Which criteria for sound CBR evaluation processes are the most important? In Round 1, panellists were asked to choose three criteria, out of a list of seven, that they considered the most important to respect in CBR program evaluation. The seven criteria and panellists' responses are presented in Table 3.

Two criteria for evaluation stood out as being the most important ones for our panel: being inclusive (35/42, 83%) and being empowering (29/42, 69%). Panellists emphasized that being inclusive means including all stakeholders who may be involved with the CBR program, from all disability and age groups, as well as others who may not usually have strong links with people with disabilities but may be indirectly affected by the program. To foster the inclusiveness of the evaluation process, one panellist stated that it is crucial to "organize the evaluation process to give a strong voice and confidence to those who often are least heard or reluctant to express their true feelings and observations". Similarly, one indicated that evaluators must ensure "that conditions for their participation are there". Concerning the second most important criterion of evaluation, "being empowering", panellists suggested that it includes building local capacity, ensuring that the decision-making power is in local stakeholders' hands and that local ownership of the evaluation process is fostered. One respondent specified: "I don't believe so much anymore in the romantic view on CBR with whole communities in charge" and preferred to see those most affected, such as CBR program team members and beneficiaries, leading. Panellists also suggested other criteria for sound CBR program evaluation processes such as paying attention to the impact of cultural differences, being participatory, and being innovative.

Panellists' responses concerning the criteria to be considered in CBR evaluation did not significantly differ in relation to their years of experience in CBR and program evaluation, the income level of their country of residence or their disability status. However, those who spent five months or more in the field each year were five times less likely to prioritize the generation of well-founded and accurate conclusions (10% compared to 50%, $p = 0.031$). In addition, individuals working for NGOs were four times more likely to prioritize actions being taken following evaluations than those working in research (67% compared to 17%, $p = 0.036$).

What are the steps in a sound CBR evaluation? In Round 1, the authors proposed eight steps for CBR program evaluation

processes and asked panellists for suggestions to refine them, and for their opinions on which one(s) should be emphasized. These steps were: (1) engaging stakeholders, (2) describing the program within its context, (3) deciding on the focus of the evaluation, (4) planning the data collection, (5) collecting the information, (6) analysing the information, (7) sharing findings and (8) taking action in light of the findings. Almost all agreed that all these steps were essential and captured most of what was necessary in a CBR program evaluation. Three of these came out as particularly important to emphasize: engaging stakeholders ($n = 18$), taking action ($n = 15$) and sharing findings ($n = 9$). For example, one panellist stated: "The engagement of the stakeholders is the most important step as it ensures a 'buy in' of the evaluation process". Another expressed that the last two steps were essential "for the CBR program and its beneficiaries to benefit from the effort". Three indicated that the process should be iterative, as one illustrated: "When I walk a step I must review the previous".

Panellists were asked to make suggestions to improve the comprehensiveness of the process. Regarding the step of stakeholders' engagement, three panellists recommended that it could be part of every step to promote "ownership" of the evaluation process. Other suggestions with regard to stakeholders' engagement include choosing the evaluator(s), becoming more familiar with the local culture, and establishing scope, sharing of responsibilities, timeline and budget. As for Step 2, "describing the program within its context", one panellist suggested the setting up of a proper monitoring system as a prerequisite, while another recommended that a baseline should be established. One indicated that Step 4 should include planning the data analysis, while another proposed that it should include pilot testing of the data collection tools and training of data collectors. In regard to Steps 7 and 8, one stated:

Not only should CBR studies be shared within the CBR program and with key CBR stakeholders to affect change (through CBR programming or advocacy/lobbying), it is important to share information with a broader CBR audience (e.g. in international forums, etc.) so others can learn from the information.

Two panellists also indicated that disseminating the results in peer-reviewed journals was important to build the evidence base for CBR and one suggested that findings should be shared in a way that empowers people to take action.

What can be done to alleviate linguistic differences? With regard to linguistic differences that may exist between evaluators and local stakeholders, a large proportion of the panel ($n = 31/42$) suggested the use of translators: "interpreters who know, relate to, and represent the local people". Although they indicated that translators should be as neutral as possible, they recognized that, realistically, people involved in the target CBR program most often played this role. Another option suggested by six panellists was to collect information directly in the local language by training local personnel to become data collectors or by learning the local language: "Interviews may be done by native speakers," "I am able to speak 5 major languages of our country, I am able to manage". Other strategies to overcome language barriers include translating tools into the local language ($n = 3$) and the use of communication aids or "visual tools that do not rely on language". Even with these strategies, many specified that evaluators must use caution when interpreting data when different languages are spoken ($n = 6$). They suggested triangulating the information obtained with field observations, and being "attentive to gestures and see if the apparent family experience seems consistent with explanations given". Nonetheless, one

Table 3. Panellists perceptions on the most important criteria for sound CBR program evaluation (Round 1).

Criteria suggested	Number of panellists who selected it as one of the three most important (%)
Being flexible	9 (21%)
Being inclusive	35 (83%)
Being empowering	29 (69%)
Being free of miscommunication	5 (12%)
Being sustainable	15 (36%)
Generating well-founded and accurate conclusions	17 (41%)
Being focused on action	16 (38%)

pointed out that “the issue is to make people participate and express in any form. The ‘culture of silence’ needs to be addressed”.

Based on Round 1 results concerning best CBR evaluation processes, the authors proposed eight recommendations to the panel in Round 2. These are presented in Table 4, along with percentage of agreement and panellists’ minor suggestions for modifications. Because more than 75% agreed that one of the most important criteria was for the process to be inclusive in Round 1, panellists were not asked whether they agreed or not with Recommendation 1 in Round 2. Nevertheless, they had the opportunity to provide suggestions to modify it. The reader should note that only the criteria for good CBR evaluations selected by 50% or more were kept for Round 2 in order to focus on the most critical elements. The criteria that were not retained will be discussed in the first author’s doctoral thesis. The panel reached consensus on Recommendations 2–8, with percentage of agreement ranging from 92% to 100%. The suggestions received mostly involve minor editing suggestions and did not change the essence of any of the recommendations.

Panellists’ opinions on sound CBR evaluation methods

With regard to methods, panellists were asked to share their opinions on the types of methodology, tools and indicators that should be favoured.

Which type of methodology should be favoured? A consensus of 76% (32/42) was obtained in Round 1 that mixed methods are best suited for CBR program evaluations. Those who preferred mixed methods indicated that they help to gather a valid and “comprehensive picture” of the program and to respond to donors’ requirements for clear impact analyses and cross-comparisons. Furthermore, one indicated that the qualitative element would “facilitate participation” and give more meaning to the process. Nonetheless, close to a quarter of our panel (9/42, 21%) believed that in certain situations, quantitative and qualitative methods alone could also be appropriate. They specified that the methodology could vary according to the evaluation question, the resources and the context. For example, one said: “If you want to know what effect a CBR program is having on school enrollment of children with disabilities, then you need to know how many children are in school. If you want to know the reasons for children with disabilities not attending local schools then you need qualitative methods to collect data”. We examined the characteristics of panellists who answered “mixed methods” compared to “depending on the situation”. No significant difference was found in relation to their experience in CBR or program evaluation, income-level of their country of residence, work in research or for an NGO and disability status. The only difference identified is that those who spent one month or more in the field each year were more likely to answer that the methodology will vary depending on the situation compared to saying mixed methods should be used in all situations (35% compared to 0%, $p = 0.015$).

Which type(s) of tools should be used? Tools are what people use to collect data. A consensus (81%, 34/42) was reached in Round 1 that both context-specific and universal data collection tools could be relevant for CBR. Panellists argued that this strategy could help to reach all lobbying targets, including local and international audiences. Many adopted a pragmatic point of view as they suggested that the choice of tool depends upon “whom you are reporting to, context and objective of the study, country situation, culture, education” and said that evaluators must “have the knowledge, skills and confidence to know when each (...) is required”. Another suggested: “if we are looking at

[sic] an universal issue we are trying to measure a universal tool is key. At the same time many people prefer to see themselves in their own context rather [sic] then compare themselves to other areas of the world”. Panellists’ profiles did not significantly influence their choice of tools.

Eighty-six percent (36/42) of the panel had used participatory or interactive tools in the past in groups or with individuals. They explained that these help to create an enjoyable and accessible climate in which “learning and reflection” are valued. Some also mentioned that they tend to “flatten the power hierarchies that often stop these people having a say” and that they were “more empowering for the local team”. Although some mentioned that these “benefit all”, many pointed to their particular relevance for “children”, for people “with communication disabilities” or who “do not have extensive schooling”, as well as for other “marginalised/disempowered” groups. Nonetheless, they require “good facilitation skills” and some perceived them as “relatively time consuming”. In addition, one indicated that care must be taken to ensure that visuals chosen are appropriate to the culture and context. On a similar note, another warned that in some contexts, “it may not be possible to use such tools in mixed gender or age groups – status requirements and gender distinctions can mean that only certain people in the group may speak or share their ideas”.

Which type(s) of indicators should be favoured? Indicators are what people measure; they are variables believed to reveal meaningful information about a program and its impact. In Round 1, the panel reached a strong consensus (90%, 38/42) that CBR evaluations should use a combination of universal and context-specific indicators. Panellists explained that context-specific indicators were essential because “context is of vital importance in CBR” since culture, social norms and policies vary greatly. Some believed that their use could also foster “local ownership” of the evaluation process. While this was important for the panel, many argued that universal indicators were absolutely needed to build the evidence base for CBR, to lobby at different levels and to allow for cross-comparison. One explained that the commonalities between programs justify the use of some universal indicators:

Some expectations of CBR programs are universal, e.g., people with disabilities are better integrated into the usual life activities of their families and communities, and there is community participation in running the program. Universal measures can be used for these factors.

Another one said: “having only context specific ones would mean no opportunity for comparison across programs and would be a lot of ‘reinventing the wheel’ for individual programs”. Panellists’ characteristics did not significantly influence their preference for universal or context-specific indicators.

Based on Round 1 findings, four recommendations associated with methods were suggested to panellists in Round 2. These are presented in Table 5 along with percentages of agreement and suggestions for modifications. The recommendations are numbered 9–12 because they follow Recommendations 1–8 presented in Table 4. Because consensus had already been reached in Round 1 for Recommendations 9–11, panellists were only asked to suggest modifications where needed. All agreed with the new recommendation (#12) on the relevance of participatory tools.

Potential frameworks for CBR evaluation

This section first clarifies whether a shared framework should be used across all CBR evaluations to define evaluation questions

Table 4. Panellists' opinions on recommendations on features of sound CBR evaluation processes (Round 2).

Recommendations	% Who agreed	Panellists' suggestions
(1) The voices of all relevant stakeholders should be included in CBR program evaluation. - This includes people from different age groups with different disabilities, gender, race and religion and playing different roles such as beneficiaries, families, staff, partners, governments, donors and other community members. Those least often heard or most marginalized should be given an opportunity to express their opinions. - Conditions for their participation to be possible need to be present. Resources available will need to be taken into consideration and innovation may be needed to give a voice to most disempowered groups.	Consensus already reached in Round 1	- Define who relevant stakeholders are ($n = 2$) - Clarify that attempts to involve everyone should be made ($n = 1$) - Clarify how participation could be facilitated ($n = 2$)
(2) The evaluation process should be designed in a way that will empower the local community, including people with disabilities. - This can include formal and informal capacity building activities such as workshops or sharing tools. Community members, including people with disabilities, may be trained to collect data. - This can also be done through a participatory evaluation process in which local stakeholders are involved and make decisions as regularly as possible.	94%	- Add that some members of the evaluation team have disabilities ($n = 1$) - Clarify what is meant by stakeholders' involvement in decisions ($n = 1$) - Clarify that this should be done "wherever feasible" ($n = 1$) - One suggests "empower people with disabilities and where possible the community at large" ($n = 1$)
(3) Evaluators should pay attention to the impact of cultural differences during a CBR evaluation and adapt as needed. - This includes taking time to become familiar with the local culture and its power structure, to explore how disability, health, education and work are viewed, and to determine if all can exercise their freedom of speech. - This also includes agreeing on a shared taxonomy, especially about disability. This also means designing the process and choosing tools in collaboration with local stakeholders.	94%	- Clarify what needs to be adapted ($n = 2$) - Ensure that it does not exclude outsiders doing the evaluation ($n = 2$) - Avoid the term taxonomy ($n = 1$) - Clarify that "key local stakeholders" should be involved ($n = 1$) - One suggests "pay attention to the local cultural practices"
(4) Evaluators should work closely with local stakeholders throughout the CBR evaluation process. For example, local stakeholders (including people with disabilities) can be involved in defining the evaluation questions, planning the data collection, collecting the information, validating the interpretations, sharing findings and deciding on the actions to be taken.	92%	- Define local stakeholders ($n = 2$): including civil society - Ensure that evaluators can keep some independence, especially concerning interpretations ($n = 1$)
(5) As appropriate, findings should be shared locally and with other audiences to advance knowledge and contribute to CBR advocacy. Written reports, community meetings, leaflets, presentations at conferences and publications in peer-reviewed journals are possible options.	100%	- Add communication modes ($n = 2$) - Clarify when ($n = 2$) - Clarify "who decides what is appropriate?" ($n = 1$)
(6) CBR program evaluations should always translate into action. - Action is defined broadly and could include: modifying program features, offering staff training on newly-raised issues, writing grant proposals rooted in evaluation results or celebrating the efforts of everyone involved in the program. - This does not entail that evaluators are necessarily responsible for the actions that need to be taken in light of the findings.	94%	- Clarify that further discussions with beneficiaries and program representatives should precede ($n = 3$) - Clarify that recommendations for actions, or feedback to inform practice, should be made ($n = 4$)
(7) Evaluators should encourage and support monitoring of CBR programs. Monitoring is the regular collection of information about the program over time. It can help establishing baseline and track progress, and can therefore greatly facilitate evaluations. When monitoring information is not available, retrospective baseline from key stakeholders or key documents review may be needed.	92%	- Clarify that record bias is possible with retrospective baseline ($n = 1$) - Clarify that monitoring should be in place before evaluation ($n = 4$) - One suggests: "recommendations for monitoring methods and tools adapted to the local context"
(8) Strategies should be used to alleviate the impact of linguistic differences. - This is important to facilitate participation of all and ensure that evaluation results are valid. - These may include: (1) using translators belonging to the local culture and who are as neutral as possible, (2) training local native speakers to collect data, (3) learning the local language, (4) using visual tools or communication aids, (5) triangulating the data collected with field observations and (6) being attentive to nonverbal cues.	100%	- Clarify that graphics could also be used with children or less literate beneficiaries ($n = 1$) - Clarify that the translator should have some understanding of CBR ($n = 1$)

Table 5. Panellists' opinions on recommendations on sound CBR evaluation methods (Round 2).

Recommendations	% Who agreed	Panellists' suggestions
(9) Mixed methods should be used when evaluating CBR programs. - Mixed methods generally enable evaluators to draw the most comprehensive picture. - The qualitative component is more likely to facilitate participation and imbue meaning to the process. - The quantitative component will help respond to donors by providing data on the numbers affected by a program and magnitude of changes following participation. - In certain rare situations, qualitative or quantitative methods alone might be better suited.	Consensus already reached in Round 1	- Clarify what it meant by mixed methods ($n = 2$) - Better explain complementation of qualitative and quantitative approaches ($n = 3$) - Methods should be fit for purpose above all ($n = 1$) - Clarify rare situations ($n = 2$)
(10) Context-specific or universal data collection tools can be used when evaluating CBR programs, as long as efforts are made to ensure that they are appropriate to the culture and program. - Tools are what we use to collect information. - Both can be relevant, and may be used on their own or together. The choice of tools will depend on their availability, the intended use of the results and personal preference. - Some may prefer to use tools developed for the specific context in which they are working (e.g. quality of life scale developed for and with the local community). - Others may prefer to use universal tools in order to make comparisons, lobby at the international level, and take advantage of what is already available (e.g. quality of life scale validated through research).	Consensus already reached in Round 1	- Clarify the statement, especially the words "or" and "both" ($n = 5$) - Clarify that other elements than preference must be considered when choosing a tool ($n = 3$): psychometric properties of the tool, match with local needs
(11) As much as possible, one should combine universal and context-specific indicators when evaluating CBR programs. - Indicators are what we measure, they are variables believed to reveal meaningful change. - Universal indicators coming from a bank of ready-to-use CBR indicators could help to lobby for CBR on the international stage. They could be useful for measuring change on desirable outcomes that are common between many CBR programs (e.g. number of children with disabilities enrolled in primary school). Care must be taken to ensure that they are appropriate for the local reality. Alone, they are unlikely to yield the full picture of the program evaluated. - Context-specific indicators are essential to capture the specificities associated with a program and the context in which it is implemented (e.g. % of farmers who employ disabled workers). Often, they can better identify unanticipated program outcomes and impacts. These indicators can be developed with local stakeholders.	Consensus already reached in Round 1	- Definition of indicators needs clarifications ($n = 2$) - Need to emphasize flexibility in their use ($n = 1$) - Would need to test the validity of universal indicators ($n = 1$) - Need clear link between aims and objectives of CBR programs and both universal and context-specific indicators ($n = 1$)
(12) Evaluators should consider using participatory tools during CBR program evaluation. These interactive tools generally rely on visuals rather than language and can facilitate the participation of all, while being especially helpful for children, as well as people with communication disabilities, with minimal formal schooling, or who are marginalized.	100%	- Clarify that they should be locally developed ($n = 1$) - Disagreement in relation to definition as it refers to visuals ($n = 1$)

and to situate findings. Panellists' opinions on which framework should play this role follow.

Should there be a shared framework for all CBR evaluations? A consensus was reached in the first round that CBR needs a shared program evaluation framework as 81% (34/42) agreed, 2% (1/42) disagreed and 17% (7/42) were undecided. The main arguments in favour of a shared framework were that this would build a solid and credible evidence base for CBR, allow for the universal characteristics of CBR programs to be compared and facilitate advocacy. For example, one expressed "Advocacy work for inclusive development requires data collection and evidence, which may be better organised in a global framework". Panellists made six suggestions concerning the development of this shared framework: (1) its purpose should be clearly stated, (2) it should not be overly complex, (3) it should not be too linear or prescriptive, rather it could be a menu, (4) there could be a place for information that

does not fit, (5) indicators could be suggested in relation to this framework and (6) participatory tools could be suggested to evaluate different components of the framework. In light of the consensus obtained, Recommendation 13 was proposed to panellists in Round 2 (Table 6). Only minor editing suggestions were made and can be found below.

Which framework should be used? Nonetheless, the content of this common framework was not agreed upon in Round 1. Panellists came very close to an agreement that the framework should be based on the CBR Matrix [1] (71%, 29/41). In fact, if we exclude those who were undecided from the analyses, 83% (29/35) agreed with this proposition in Round 1. Only half of the panel agreed that evaluations should follow the Evaluation Hierarchy [19] starting with analyses of relevance, and then moving to process, outcomes and cost analyses (51%, 21/41 agreed). In Round 1, five individuals highlighted that CBR principles [2] based on the

Table 6. Panellists’ opinions on recommendation on a shared framework for CBR evaluation (Round 2).

Recommendation	Panellists’ suggestions
(13) CBR program evaluations should be situated within a shared framework. • A framework is a model to guide one’s thinking when designing a program evaluation. • One of the main advantages of having a common framework among all people involved in CBR program evaluations would be to situate evaluation findings within this framework. This could: (1) enable the CBR community to join forces in building the evidence base regarding the effectiveness of this strategy, (2) facilitate communication and advocacy, and (3) facilitate useful comparisons across the more universal features of CBR programs. A shared framework could also provide a common understanding of what CBR aims to achieve and how.	• Confusion in relation to whom the framework would be for ($n = 2$) • Avoid the term “join forces” in an international context ($n = 1$)

United Nations Convention on the Rights of Persons with Disabilities [20] were important and could be cross-cutting elements. Other suggestions include: (1) inputs and outputs should have a clear space ($n = 2$), (2) it should not be exclusively centred on activities ($n = 1$), (3) viability and external support should be included ($n = 1$) and (4) quality of life should be emphasized ($n = 1$).

Because no consensus was reached, three new framework propositions were provided in Round 2, based on the suggestions received. These are: (1) the CBR Matrix [1] alone is sufficient, (2) the CBR Principles [2] (i.e. autonomy, inclusion, participation, empowerment, sustainability and multisectoral collaboration) alone are sufficient and (3) the CBR Matrix and the CBR Principles should be combined. Furthermore, to take into account all the suggestions made in Round 1, the authors suggested to the panel that they should first attempt to agree on a shared framework that could be used in a flexible way and complemented with a list of other elements that can be evaluated. Panellists’ opinions on all frameworks propositions (Rounds 1 and 2) are presented in Figure 2. The CBR Matrix [1] appears twice because panellists had to say whether they agreed that the framework should be based on the CBR Matrix in Round 1, while in Round 2 they were invited to consider the CBR Matrix alone as a framework for CBR evaluation.

In Round 2, a consensus (83% agreed, 61% of which strongly agreed) was achieved that a shared framework for CBR evaluation should combine the CBR Matrix [1] and the CBR Principles [2]. A visual representation of this framework, as it was proposed to panellists, can be found in Appendix A. The main reasons given for preferring this option included its comprehensiveness and its potential to demonstrate impact. For example, one panellist mentioned:

The framework could help determine/demonstrate how these rehabilitation services have helped to facilitate autonomy and greater inclusion in society in domains such as education and employment

while another said to look at both access and participation. Many [sic] of times, we may find PWDs [people with disabilities] will have access [sic] eg had received an assistive device) but this may not reflect clearly on their participation level.

Although a weakness of this option was its complexity, three specified that it was not that complex. For example, one said:

I very much appreciate the joining of the Matrix and the Principles. Yes, it could be complicated, but examples can be

provided to show that by taking only specific components of it, a CBR program can develop an evaluation process very relevant to its specific goals.

Other suggestions received in Round 2, each by one panellist, include using the most relevant framework for the situation out of the three proposed, using the *Joint Position Statement* on CBR [21], focussing on looking at whether inclusion with dignity is achieved for each element of the CBR Matrix, summarizing the CBR Principles more clearly, mapping out objectives for each program and evaluating whether they have been met, adding space for information that does not fit, clarifying that only the components relevant to the situation should be used, and exploring the framework components with program representatives “in the form of a relaxed discussion”.

Analyses were conducted to investigate whether preferences for one framework over another could be associated with panellists’ characteristics (i.e. CBR experience, program evaluation experience, time in the field, income-level of their country of residence, work in research or for an NGO and disability status). However, because many panellists were undecided in Round 1, the numbers were too small in many categories and Fisher Exact Tests became unsuitable. The one finding that was significant was that those who spent five months or more in the field each year appeared more likely to agree that evaluations should start with analyses of relevance and then move to process, outcomes and costs (78% compared to 44%). In Round 2, researchers removed the “undecided” option from the questionnaire and were therefore able to conduct inferential analyses. Although none of these relationships is statistically significant, those who had more than 10 years of experience in CBR (89% compared to 67%, $p = 0.151$) and those living in low- or middle-income countries (94% compared to 75%, $p = 0.196$) appeared more likely to agree that the shared framework should combine the CBR Matrix [1] and the CBR Principles [2].

Discussion

Although a number of studies have contributed to the debate on how to evaluate CBR programs [10], this is the first published study to have generated consensus on best evaluative practices in CBR. In regard to the panel’s credibility, the 42 members of the CBR community who contributed compose an experienced and heterogeneous panel. Individuals from a wide range of backgrounds and geographical areas were recruited, many of whom were very experienced in CBR and recognized as leaders in this field. In addition, good response rates were achieved in both rounds [14]. The group reached consensus on 13

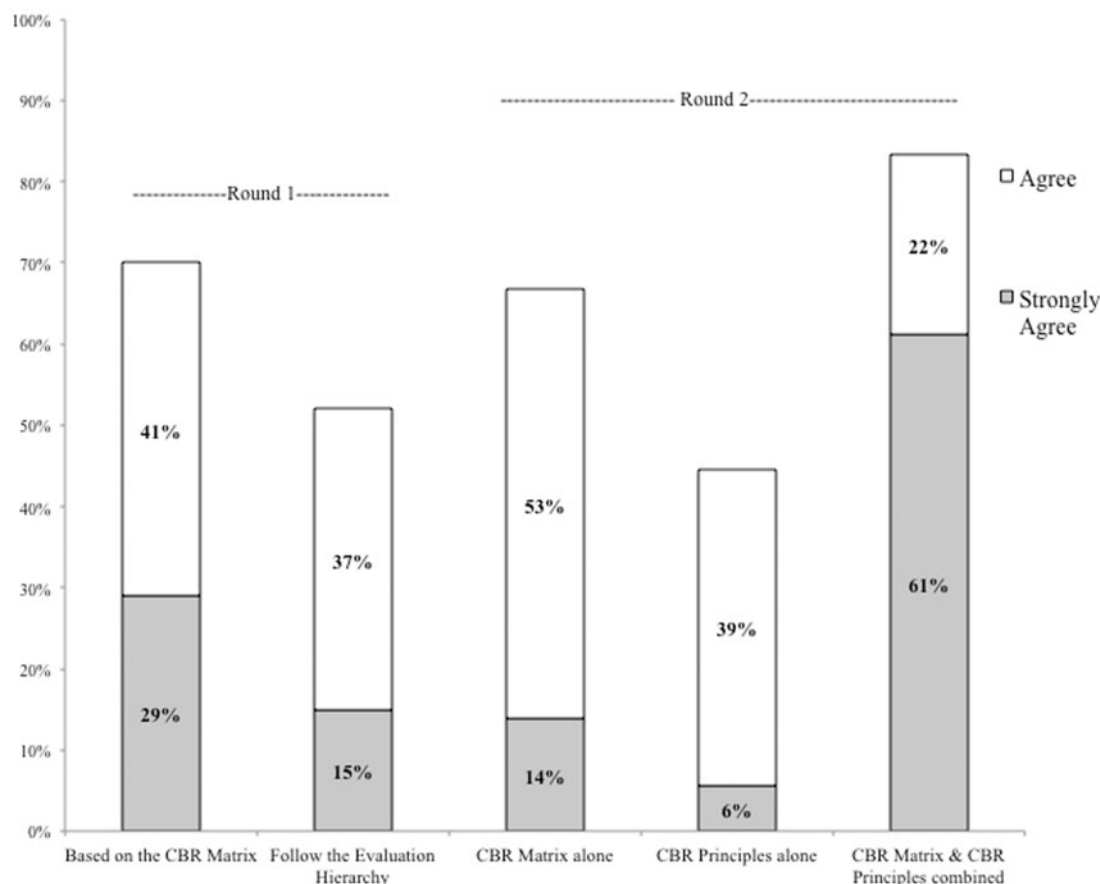


Figure 2. Bar graph showing percentages of panellists who agreed with propositions for a shared framework for CBR evaluation.

recommendations about evaluation processes, methods and frameworks (Appendix B).

First, the panel agreed on the key features of sound CBR evaluation processes:

- (1) *Inclusive*: Attempts to include the voices of all relevant stakeholders should be made.
- (2) *Participatory*: Close collaboration with key local stakeholders is needed throughout the process.
- (3) *Empowering*: The process should be designed in a way that promotes the empowerment of key local stakeholders.
- (4) *Respectful of local cultures and languages*: Efforts and strategies are required to alleviate the impact of potential differences between evaluators and local stakeholders.

In line with CBR's philosophy and existing practice, people with disabilities and their families were most often mentioned as key stakeholders to include, collaborate with and empower through the evaluation process. While Features 1, 2 and 4 emerged more often in the CBR evaluation literature [7,8,10,11,22,23], very few authors had specifically suggested that CBR evaluations should be empowering to the local community [10,11,22]. Panellists' opinions on the most critical steps of sound CBR evaluations processes are strongly congruent with indications found in the CBR literature [22–24]: both indicate that “engaging stakeholders”, “sharing findings” and, “taking action” should be emphasized. To facilitate implementation of the four above-mentioned principles, an eight-step process for CBR evaluations is proposed in Figure 3. Stars in the figure stress the importance of the three most critical steps of sound CBR evaluation. Since the panel suggested that efforts to engage local stakeholders should be made throughout the entire

process, it is linked with each and every step. This is strongly congruent with a participatory evaluation approach [25], as well as Boyce and Ballantyne's [22] suggestion that people with disabilities should be involved in all the steps. Guidance on how to ensure that these four principles are respected can also be found in empowerment evaluation [26] and utilization-focused evaluation [25].

Second, with regard to methods, the panel reached consensus that mixed methods should be favoured in most CBR program evaluations. This is in line with recommendations found in the CBR literature [4,27], although qualitative methodologies have been used more often in CBR program evaluations. Nonetheless, the panel highlighted that, in some cases, qualitative and quantitative methods alone might be better suited. Evaluators should consider which type of methods would best suit the evaluation objectives taking into account the available resources and the local culture. A consensus was also achieved that CBR evaluations should ideally use a combination of universal and context-specific indicators in order to respond to both cross-comparison requirements and local needs. As a consequence, although a bank of ready-to-use indicators for all CBR programs could be useful [25], our findings indicate that complementation with locally generated indicators is key. This is congruent with findings from a field study in South Africa [11], which highlighted the need to give a voice to local stakeholders when selecting indicators, as the desirable outcomes suggested in the CBR Guidelines [2] did not reflect their perception of the most important indicator of change following participation in the program. Similarly, both universal and context-specific data collection tools, such as checklists or interview guides for

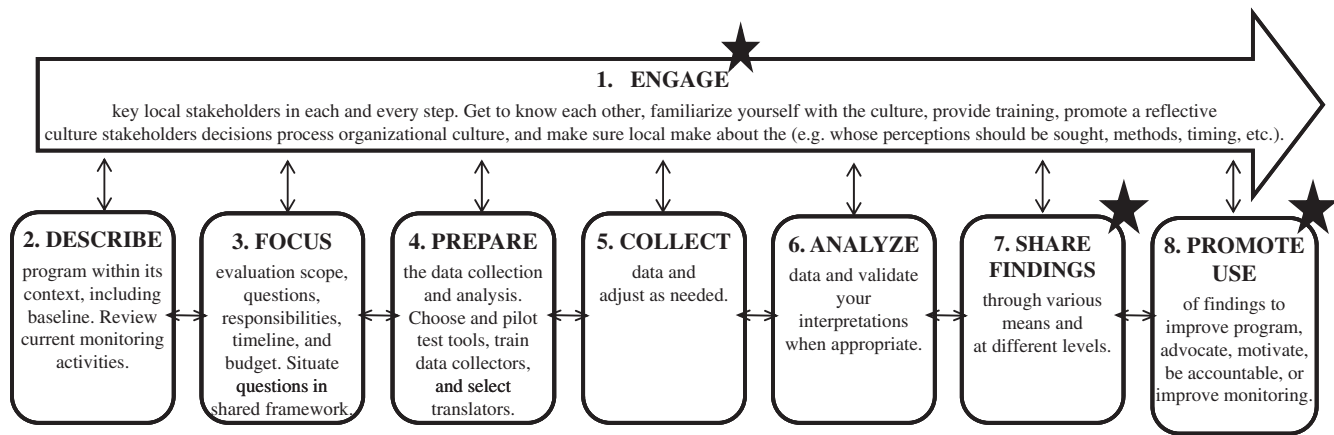


Figure 3. A step-by-step approach to CBR program evaluation.

discussion groups, were perceived as relevant for CBR evaluation. This implies that one or the other, or both, could be used for an evaluation, depending upon fit for purpose. The process suggested by Adeoye et al. [8] to develop evaluation tools for CBR and the criteria to select tools proposed by Lukersmith et al. [9] could be useful on that matter. Furthermore, all panellists agreed that participatory tools are very suitable for CBR evaluations as they could facilitate the participation of all, and especially of the most marginalized, those with communication disabilities, those with low educational achievement, and children. This agrees with indications from experiences reported in the CBR literature [11,28,29] and with the accessibility and inclusion principles of the *Convention on the Rights of Persons with Disabilities* [20]. Thus, the authors strongly recommend that initiatives to build capacity in CBR evaluation, such as the production of manuals or training programs, include a selection a participatory tools, as well as guidance on how to moderate discussions using these tools.

On another point, the panel also reached a consensus that it would be beneficial to share a common framework across all CBR evaluations. This framework could be used to determine evaluation questions, prepare data collection tools, structure data analysis and situate findings in evaluation reports. This could help to build a more cohesive evidence base for the effectiveness of CBR, as the wide range of frameworks found in the CBR literature makes the combination of findings particularly challenging [5,10]. The panel reached consensus that this framework should combine the CBR Matrix [1] and the general principles guiding CBR [2] (Appendix A). Despite this, in light of the comments received, the authors feel that further discussions and negotiations among representatives of the CBR community are required to finalize this common framework. In line with findings from a field study on CBR program evaluation [11], experts stressed that the common framework should remain very flexible. Thus, the authors recommend to those engaged in CBR program evaluations to use a flexible combination of the CBR Matrix and the CBR Principles and to share their experience.

This study has a number of strengths and limitations. The use of two formats (i.e. Internet and mail) only slightly increased the response rates as very few used the hard copies provided. The authors believe that the individual attention given to each potential panel member and the reminders used were effective in encouraging participation. In Round 2, for example, 25% responded in the three days following the first reminder and 19% following the second one. In an ideal scenario, more panellists who are directly involved in CBR programs on a day-to-day basis

and coming from low- and middle-income countries would have been recruited. The fact that the questionnaires were only available in English might partly explain this limitation. The authors recognize that some of the suggestions received in Round 2 could not be fully explored in the context of a Delphi study with two predefined rounds. Although the methodology provided less space for debate and negotiations between group members than a face-to-face meeting, it was effective at gathering a very credible experts panel coming from diverse geographical areas and using minimal resources. The authors recognize that the recommendations developed and the eight-step process generated need to be detailed, piloted, and linked with tools to be most useful.

Conclusion

This study was successful in generating consensus about best evaluative practices in CBR among a panel of diverse and experienced representatives from the CBR community. It is hoped that this will provide guidance to those who evaluate CBR programs as well as to those requesting CBR program evaluations. Efforts are now required to translate this new knowledge into guidelines that include suggestions for implementation and are linked to tools and training opportunities. Ideally, these initiatives would strongly rely on participatory tools and pilot testing in a broad range of CBR contexts. In doing so, they would yield the valid and reliable data necessary to establish the evidence base for CBR.

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Appendix A. Shared framework for CBR program evaluations accepted by 83% of the panel.

		CBR Principles					
		Autonomy	Inclusion	Participation	Empowerment	Sustainability	Multisectoral collaboration
CBR Matrix	Health Promotion Prevention Medical care Rehabilitation Assistive devices						
	Education Early childhood Primary Secondary & higher Non-formal Lifelong learning						
	Livelihood Skills development Self-employment Wage employment Financial services Social protection						
	Social Personal assistance Relationships, marr. & family Culture & arts Recreation, leisure & sports Justice						
	Empowerment Advocacy & communication Community mobilization Political participation Self-help groups DPOs						

Note. Includes the CBR Matrix [1] and a summary of the CBR Principles [2]

Appendix B

Summary of recommendations for best practices in community-based rehabilitation evaluation:

- (1) Attempts should be made to include the voices of all relevant stakeholders in CBR program evaluations.
- (2) Wherever feasible, the evaluation process should be designed in a way that will empower key local stakeholders, including people with disabilities.
- (3) Evaluators should pay attention to the impact of cultural differences during a CBR evaluation and adapt as needed.
- (4) Evaluators should work closely with key local stakeholders throughout the CBR evaluation process.
- (5) Findings should be shared locally and with other audiences when appropriate to advance knowledge and contribute to CBR advocacy.
- (6) Evaluators should promote use of findings from CBR evaluations.
- (7) Whenever appropriate, external evaluators should make concrete recommendations in regard to monitoring of the CBR program concern, taking into account its particularities and context.
- (8) Strategies should be used to alleviate the impact of linguistic differences on participation and validity (e.g. translators, local data collectors, learning the language, visual tools, complementing with observations and attention to nonverbal cues).
- (9) Mixed methods should be strongly considered when evaluating CBR programs.
- (10) CBR evaluators should choose data collection tools that are fit for purpose (i.e. appropriate to the needs, culture, program, and resources, and have been tested whenever possible). Those can include context-specific and universal data collection tools.
- (11) As much as possible, one should combine universal and context-specific indicators when evaluating CBR programs.
- (12) Evaluators should strongly consider using participatory tools during CBR program evaluations.
- (13) CBR program evaluations should be situated within a shared, but flexible, framework. More discussion is needed to clarify the exact content of this framework, but it should combine the CBR Matrix [1] and the CBR Principles [2].

5.2 Additional Information on Panellists' Opinions

Because of constraints associated with manuscript length, some of the findings could not be included above. These cover explanations on the criteria for sound CBR evaluation processes, data collection methods panellists are most likely to use, strategies to ensure a good community-method fit, and pros and cons of potential shared frameworks for CBR evaluation.

5.2.1 Explanations on the criteria for sound CBR evaluation processes. In the first round, panellists were asked to select the three most important criteria out of a list of seven. Although other criteria might also have generated a high level of consensus if we had asked whether or not panellists agreed that these were key features of sound evaluation processes, we preferred to focus on the most critical features in order to keep the guidelines accessible and manageable for people involved in CBR.

In Round 1, panellists also made suggestions to modify the way the criteria were named and provided further explanations concerning their rating of the initial criteria suggested. In regard to generating well-founded and accurate conclusions, two panellists shared: “too often the conclusions appear to be more anecdotal” and “very key for anyone to listen to you ever again”. As for sustainability, a few panellists indicated that evaluations should not depend on a lot of resources, that they should be realistic and manageable. Two specified that by ensuring that people with disabilities are included and empowered through the process, the evaluation should be more sustainable. One said: “I am not sure if an evaluation process needs to be sustainable. CBR should be, but I am not sure evaluation should be too.” In respect to flexibility, one indicated: “It won’t happen unless you are flexible”. Four added that programs and contexts vary greatly and thus, evaluations must match this reality. Concerning the criterion ‘being focused on action’, one panellist expressed: “I recall evaluations that were done and then there were no resources to take the corrective actions (...) Why evaluate?!” One suggested that this criterion

should be called “use the results for constant progress and social change”. As for the criterion ‘being free of miscommunication’, one suggested that communication should be clear, that each other’s taxonomy should be examined, and that “no false expectations [be] raised about what findings will be used for”.

5.2.2 Data collection methods panellists would most likely use and why. In a ranking question (Round 1), panellists were asked which data collection methods they would most likely use during a CBR program evaluation out of a list of eight. The results are presented in Table 5.1. These include the number of panellists ranking each method first (the most likely), second, third, fourth and fifth, and the sum for each data collection method if five points are given each time it is ranked first, four points when it is ranked second, and so on.

Table 5.1

Data Collection Methods Panellists Would Most Likely Use

	1: The most likely <i>n</i> (%)	2 <i>n</i> (%)	3 <i>n</i> (%)	4 <i>n</i> (%)	5 <i>n</i> (%)	Sum (weighting)
Discussion groups	13 (41%)	6 (19%)	5 (16%)	5 (16%)	3 (9%)	117
Individual interviews	2 (7%)	5 (17%)	12 (41%)	6 (21%)	4 (14%)	82
Written surveys/questionnaires	2 (12%)	3 (19%)	1 (6%)	5 (31%)	5 (31%)	40
Observations	6 (21%)	9 (31%)	7 (24%)	6 (21%)	1 (3%)	100
Individual assessments	2 (13%)	2 (13%)	0 (0%)	4 (27%)	7 (47%)	33
Review of statistics	0 (0%)	3 (33%)	2 (22%)	0 (0%)	4 (44%)	22
Review of documents	6 (24%)	4 (16%)	4 (16%)	5 (20%)	6 (24%)	74
Photovoice	0 (0%)	0 (0%)	1 (33%)	1 (33%)	1 (33%)	6

The sum obtained for each method indicates that discussion groups were the most popular among the panel, followed by observations, individual interviews, and review of documents respectively. Concerning discussion groups, one panellist said that these were “powerful tools for getting rich data and stories of change”, while another stated that they were “feasible to organize”, not requiring too much time. One suggested that participatory tools could be used

during discussion groups to facilitate engagement. In regard to individual interviews, one mentioned: “it is more likely that structured interviews will pose appropriate questions to the appropriate people” while another saw it as an opportunity to “share their positive and negative experiences” freely. A few participants specified that key people to interview include: CBR beneficiaries, families, service providers, community leaders, governments, as well as relevant partners such as NGOs and schools. Furthermore, four panellists indicated that they would often combine interviews or discussions groups with observations “to confirm what has been learned”. The latter includes observations of program activities, along with community and home visits. One recommended participant-observation and said: “being with the stakeholders in the offices, in the communities and homes, and with the collaborating services”. Review of program documents was seen as a way to gain a “first comprehensive understanding of the program” and to see “how the program presents itself”, while providing an overview of its monitoring activities. One panellist advised that caution must be taken, as this type of data might be “skewed or misleading”.

Regarding reviewing statistics, it was seen as useful “to compare the impact made by the project with the national or global level” although two participants questioned their reliability, availability, and representativeness of the social vision of disability. The panel was divided as to whether written surveys and questionnaires could be appropriate for CBR. While some indicated that these “help to determine the most commonly noted issues” and “that people may be more able to express criticism in this indirect format”, others saw these as “so problematic in different languages with people often with poor literacy and numeracy (...) these would be the very last port of call”. Similarly, one expressed that these were: “hard in my geographical and cultural region, as people try to find the “right” answer to please the visitor”. Others suggested using

these in conjunction with a more participatory method or “when the appropriate questions are known”. Few panellists were likely to use Photovoice: two mentioned that it appears time consuming while another saw it as a tool “to encourage discussion in a focus group or with an individual” rather than a data collection method per say. Nevertheless, one believed that it is a “strong means to get unexpected stories and new insights”.

Similarly, two suggested that “pictures, stories, letters” and “drawings” could encourage discussion. One said that he or she liked the methodology developed for CBR by Cornielje and colleagues (2008), in which flow charts guide data collection. A large number of panellists proposed using participatory tools from “participatory rural appraisal” (PRA), “outcome mapping” or “most significant change” to facilitate participation and gather meaningful data. Suggested tools include: “ranking, sorting exercises” and “mapping exercise to visualise how a CBR program is connected”.

5.2.3 Strategies to foster a good community-method fit. When asked what they did to ensure that their data collection methods were suitable for the community in which they worked, five main themes emerged from panellists’ suggestions. The first one, cited by almost all panellists, was to develop a strong partnership with local partners through “mutual respect”, discussing “with involved members of the community, what might be the most effective way to gather useful information” and “ensure that you have a local person in your team who understands the nitty gritty... speaks the language and comes from same culture”. The second strategy, brought up by five experts, was to obtain enough information to develop a “thorough understanding of the context”. Three panellists suggested adapting data collection methods to the culture and language. Furthermore, one indicated that having a “good understanding of CBR”

was a pre-requisite and four suggested that participatory methods were very often appropriate since “in most communities, oral and visual methods work well”.

5.2.4 Pros and cons of potential shared frameworks for CBR evaluation proposed.

Panellists also shared their thoughts on the main pros and cons of the potential shared frameworks for CBR evaluation proposed. Their comments on all the frameworks for which consensus was not reached are presented in Table 5.2.

Table 5.2

Panellists' Perceptions of the Pros and Cons of the Frameworks for CBR Evaluation Proposed

Suggested Framework	Pros	Cons
Based on CBR Matrix [1]	- Widely known and accepted ($n=3$) - Represents CBR today ($n=6$)	- Too complex and vague ($n=2$) - CBR principles should be represented ($n=4$) - Unknown to people outside the disability sector ($n=1$)
Based on the Evaluation Hierarchy [22]	- Covers essential elements ($n=2$) - To highlight the importance of relevance ($n=4$) - For funding and advocacy ($n=2$)	- Too complex ($n=3$) - Cost does not seem appropriate ($n=1$) - Relevance is too tricky to evaluate ($n=2$) - Outcomes and impact should be emphasized ($n=2$) - A hierarchy might not be appropriate ($n=1$)
CBR Matrix [1] alone	- Covers essential elements ($n=3$) - Is supported by major documents such as the <i>CBR Guidelines</i> (2010) ($n=1$) - Not too complicated since people are familiar with it ($n=2$)	- Presentation in matrix format may be disconcerting ($n=1$) - Critical elements are missing ($n=4$): such as religion, environment, and sustainability. - Could encourage work in silos and discourage genuine reflection ($n=3$) - Empowerment is not well accommodated as a cross-cutting issue ($n=1$)
CBR Principles [2] alone	- Encourage further reflection about the program ($n=1$) - Emphasize impact ($n=1$)	- Some principles need clarification ($n=2$) - Does not provide enough structure ($n=5$)

5.3 Conclusion

In this Delphi study, 42 experts from all around the world reached consensus on key features of best evaluative practices in CBR. The findings emphasize the importance for CBR evaluation processes to be inclusive, participatory, empowering and respectful of local cultures and languages. Furthermore, the consensus generated suggests that CBR evaluators should seriously consider using mixed methods, combining universal indicators with others generated with the local community, and using participatory tools to facilitate the active engagement of all in evaluation activities. The panel also reached consensus on the value of sharing a common framework across all CBR evaluations, which should combine the CBR Matrix (ILO, UNESCO, & WHO, 2004) and the principles guiding CBR (WHO, UNESCO, ILO, & IDDC, 2010). This Delphi study has generated significant insights and the much-needed consensus on best practices in CBR evaluation. The practice guidelines generated and my final model for best practices in CBR program evaluation follow in Chapter 6. These were developed, validated and refined through the three phases of this research process: the systematic review, the field study, and the experts consultation.

Chapter 6: Best Practice Guidelines and Model for Community-Based Rehabilitation Program Evaluation

This thesis aimed to define best evaluative practices in community-based rehabilitation (CBR) and develop rigorous, comprehensive, reliable and applicable guidelines. This was achieved through a sequential mixed methods design including three research phases: a literature review, a field study, and an experts consultation. This chapter integrates insights gained through the three phases. It first highlights the main lessons learned in each phase and then presents the practice guidelines for sound CBR program evaluation. The guidelines provide directions to carry CBR program evaluation that matches sound evaluative practice, aligns with CBR values of inclusion, participation and empowerment, while being applicable in diverse cultural contexts. Furthermore, the guidelines should foster the creation of a more cohesive evidence base for CBR as they suggest situating results from CBR program evaluations and studies into a shared framework. Explanations on how each guideline emerged, was validated, and was refined through the three research phases follow the guidelines. A model appears at the end of the chapter to summarize and organize key features of best evaluative practices in CBR into three categories: sound evaluation processes, recommended frameworks, and suitable methods.

6.1 Main Lessons Learned in the Three Research Phases

This section presents the main lessons learned in the literature review (Phase 1), the field study (Phase 2) and the experts consultation (Phase 3). This clarifies how the first phase led to the development of an initial proposition for best practices in CBR evaluation, how the second one helped to ensure the guidelines generated would be applicable to the field, and how the last one yielded the necessary expert consensus and brought essential nuances to the guidelines.

6.1.1 Main lessons learned in Phase 1: Literature review. Phase 1 consisted of a systematic literature review and analysis on CBR program evaluation (Grandisson, Hébert, &

Thibeault, 2014), and of a thorough analysis of suitable evaluation theories. While it indicated that qualitative methodologies had dominated the CBR scene, some authors called for the integration of mixed methods to strengthen CBR's evidence base (Wirz & Thomas, 2002; Cornielje et al., 2008; Zhao & Kwok, 1999). Two of the articles retrieved pointed to the usefulness of participatory tools to maximize engagement of less literate or disabled individuals in CBR evaluation activities (Kuipers & Harknett, 2008; Sharma, 2004). Although only one article (Boyce & Ballantyne, 2000) specifically suggested CBR program evaluation should be empowering, this was deemed paramount by the author in order to respect CBR philosophy. Fortunately, empowerment evaluation provided guidance in this area (Fetterman & Wandersman, 2005) and helped design the program evaluation conducted in Phase 2. The review also highlighted diverging views on whether context-specific or universal tools and indicators should be favoured (Adeoye et al., 2011; Chung et al., 2011; Wirz & Thomas, 2002). Evaluation theorists emphasized the necessity to closely collaborate with local stakeholders and to include all perspectives, calling for efforts to enable those who are marginalized to participate (Fetterman & Wandersman, 2005; Green & Kreuter, 2005; Mertens, 2009; Patton, 2012).

This literature review enabled the doctoral candidate to develop an initial model for best practices in CBR program evaluation, including seven potential features of sound evaluative practice in CBR and eight potential steps. It highlighted the need to closely collaborate with local stakeholders and empower them through the evaluation process, and the necessity to integrate feedback loops to promote the use of findings for decision-making. It also stressed the need for actions to facilitate the active participation of people with disabilities in data collection, through the use of participatory tools for example. The model provided as much guidance as was possible, extrapolating from the literature. Yet, it needed significant adjustments in a real-life

CBR program evaluation and through experts' opinions to identify the most critical features and steps, to generate consensus, and to foster its clarity, comprehensiveness and applicability.

In respect to the use of frameworks to situate CBR evaluation results, 13 different ones were retrieved in the systematic review and none had been used more than once. Because none stood out as being clear, comprehensive and applicable to diverse evaluation contexts, a framework combining the CBR Matrix (ILO, UNESCO, & IDDC, 2004b) and the Evaluation Hierarchy (Rossi et al., 2004) was developed after Phase 1 in an attempt to build a more solid and cohesive evidence base for CBR. A recommendation on this matter was included in the best practice model generated in Phase 1: it stated that, when evaluators and stakeholders clarify the evaluation focus, they should situate evaluation questions within this shared framework.

6.1.2 Main lessons learned in Phase 2: Field study. In Phase 2, a South African CBR program was evaluated according to the initial model and framework designed in Phase 1. Based on this experience, several strategies pivotal to CBR evaluation were identified (Grandisson, Thibeault, Hébert & Templeton, 2014). The findings reinforced that evaluators should develop strong partnerships with program stakeholders and provided directions on the strategies to do so: engaging in egalitarian and nonjudgmental relationships, respecting local pace, and clarifying each other's expectations appeared essential. They also highlighted some of the challenges inherent to the range of cultural settings in which CBR is implemented as they called for evaluators' sensitivity to different visions of disability and rehabilitation. While participatory tools emerged as critical to active engagement of all groups, the use of multiple data collection methods and sources was key to the gathering of an accurate and comprehensive picture of the program's strengths, weaknesses, and impact. Giving a voice to all groups while reassuring them

that their opinions would be reported as a group, and not as individuals, appeared to have boosted confidence in the evaluation and sense of belonging to the program.

This field study confirmed empowerment evaluation's (Fetterman & Wandersman, 2005) suitability for CBR as capacity building efforts and the learning climate created were widely appreciated. Lessons learned indicated that creativity and flexibility are key abilities since it was necessary to develop local strategies to build evaluative capacity and maximize participation in evaluation activities. For example, informal capacity building strategies, such as gradually delegating evaluation roles and sharing tools as needs emerged, were more effective than a workshop teaching pre-determined steps.

While the framework designed in Phase 1 proved useful to situate evaluation questions and findings, the necessity of flexibility was emphasized: local representatives modified the labels of some categories and added groups of children affected by their program in the figure. In summary, the second phase helped refine the best practice model. It highlighted challenges and potential strategies associated with carrying an empowering CBR program evaluation when evaluators and local stakeholders have different cultural backgrounds. The changes made after Phase 2 mainly enhanced the model's applicability and comprehensiveness, while providing real-life applications of how a CBR program evaluation can follow best evaluative practices.

6.1.3 Main lessons learned in Phase 3: Experts consultation. Finally, experts from the CBR community were surveyed on the recommendations stemming from the first two phases using a Delphi study (Grandisson, Thibeault, Hébert, & Cameron, 2015). They reached consensus on key features of best evaluative practices in CBR. Yet, they did much more than endorse a range of potential recommendations for sound CBR program evaluation. They also considerably fleshed out the initial practice statements with essential nuances and suggestions.

Experts took position and agreed on which were the most critical features of sound CBR evaluation out of the list of features emerging from Phases 1 and 2: they rated being inclusive and being empowering particularly highly. They stated that, in CBR, key stakeholders include people from all disability and age groups, as well as others who may be indirectly affected by the program. They added that enabling conditions should be created to allow all to share their perspectives freely. While experts agreed that evaluators should closely collaborate with local stakeholders during the process and attempt to empower the local community, they stressed that the stakeholders' degree of involvement and extent to which they will be empowered will vary greatly depending on objectives, interests, skills, and resources. In line with Phase 2 findings (Grandisson, Thibeault, et al., 2014), they also pointed to the necessity of respecting local cultures and languages and suggested a range of strategies to do so. In addition, they called for more attention to be given to CBR program monitoring and suggested that CBR evaluators should make recommendations on this matter whenever appropriate. Experts perceived three evaluation steps as particularly critical in the model: engaging stakeholders, sharing findings and taking action. They specified that stakeholders should be engaged in the entire process, not only at the beginning as initially illustrated in the eight-step process developed in Phases 1 and 2. They also clarified that evaluators are not responsible for taking action following an evaluation, but should rather foster the use of findings by local representatives. This point further validated the suitability of empowerment evaluation (Fetterman & Wandersman, 2005), as it reinforced the fact that evaluators should only act as advisors to the key local stakeholders ultimately responsible for making decisions on the evaluation process and its follow-up.

Regarding methods, the group also concurred that evaluations should combine universal and context-specific indicators as much as possible, and that both context-specific and universal

data collection tools are relevant. Experts agreed that mixed methods and participatory tools should generally be favoured, although they stressed goodness of fit as being most important. Consequently, goodness of fit emerged as a guideline for sound CBR evaluation and replaced the previous proposition that either context-specific or universal data collection could be used.

The experts' priorities and suggestions were added to the guidelines developed in the first two phases: they included the importance of inclusiveness and of ongoing collaboration, specified criteria on which evaluation decisions should be founded, and clarified the evaluator's role in regard to monitoring and taking action. In relation to the shared framework in which to situate evaluations, the panel reached consensus that a common CBR evaluation framework was paramount, mostly to foster the building of a more solid and cohesive evidence base for CBR and, in turn, to facilitate advocacy work. Experts agreed with the author's proposition that the CBR Matrix (ILO, UNESCO, & WHO, 2004b) should constitute part of this framework, but rejected the Evaluation Hierarchy (Rossi et al., 2014). Four panel members suggested that the CBR Principles (WHO, UNESCO, ILO, & IDDC, 2010) should complete the framework and the group reached consensus on this regard. They highlighted the need for flexibility when using the framework and made suggestions on how to achieve this.

6.2 Best Practice Guidelines for CBR Program Evaluation

This section offers 10 best practice guidelines for CBR program evaluation, along with suggestions for implementation (Table 6.1). The guidelines should foster sound evaluation decisions regarding processes, framework(s), and methods. The evaluation context, objectives and available resources must also be taken into account. All 10 guidelines are supported by findings from the literature review and the field study, and represent expert consensus. Explanations on the systematic development of each guideline follow the table to clarify how the guidelines emerged, were validated, and were adjusted through the three research phases.

Table 6.1

*Best Practice Guidelines for CBR Program Evaluation***Guideline 1: Participatory evaluation process****Evaluators and key local stakeholders should collaborate closely throughout the entire program evaluation process.**

- An advisory group should be formed. Its composition will vary, but must include representatives of key local stakeholder groups such as people with disabilities, program managers, employees, volunteers, local partners, governments or donors. The advisory group should ensure that individuals from different genders, age groups, religions, ethnicity and socioeconomic status are invited to participate.
- Groups' and individuals' degree of involvement will vary depending on the situation. Evaluators present different options with their pros and cons. Local stakeholders help define evaluation questions, contribute to evaluation decisions, provide information about the local context, and offer opinions on suitable methods. They may be active throughout the process: describing the program, focusing the evaluation, planning data collection and analysis, collecting data, validating interpretations, sharing findings, and promoting use of findings.
- Engaging in egalitarian and non-judgemental relationships, respecting local pace and clarifying each other's expectations are essential strategies.
- Evaluators remain responsible for the generation of well-founded and accurate conclusions. Thus, in some contexts, they will need to keep some independence when finalizing their evaluation report in order for the findings to be trusted by a range of audiences.

Guideline 2: Empowering evaluation process**The program evaluation process should be designed to empower key local stakeholders, including people with disabilities.**

- Since empowerment arises from giving a voice to the least often heard, the evaluation process should enshrine in its process the specific consultation of all vulnerable stakeholders.
- A participatory evaluation process in which local stakeholders are involved and make decisions as regularly as possible concerning, for example, evaluation focus, methods, and what to do with the findings constitutes another essential strategy. Evaluators act as advisors, suggesting options and sharing their perception on pros and cons.
- Using the process to transfer knowledge and give control to local stakeholders enhances empowerment. This includes formal and informal capacity building activities: workshops, sharing tools, delegating evaluation roles, and fostering a reflective culture in which program decisions rest on evaluation insights. Community members, including some with disabilities, may be trained to collect or analyze data. The use of participatory tools can be empowering.
- Sharing findings and promoting use of findings to improve a situation can also enhance control. Findings should clearly document the program's impact and the conditions conducive to its success. They should be shared in a way that empowers local stakeholders to take action and be accountable at different levels (e.g. written reports, community meetings, leaflets, posters, presentations at conferences, radio announcements, short videos, and collaborative publications in peer-reviewed journals). Program representatives should be involved in deciding how findings will be used: modifying program features, offering staff training on newly-raised issues, writing grant proposals rooted in evaluation results, changing the program's monitoring tools and activities, or celebrating everyone's efforts. Evaluators are not usually responsible for taking actions, but rather that they should promote findings use.

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- The extent to which evaluation can be empowering will vary according to many factors such as local stakeholders' interests and skills, resources, and evaluation objectives and context.
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Guideline 3: Embracing cultural diversity in the evaluation process

Evaluators should pay attention to the impact of cultural differences throughout the program evaluation process and adapt as needed.

- This includes taking time to become familiar with the local culture and its power structure, to explore how disability, health, education, and work are viewed, and to determine if all can exercise their freedom of speech. This also includes agreeing on a shared terminology, especially about disability. Personal research, time spent in the community and respectful discussions with local representatives can help gain greater community knowledge.
 - Designing the process and choosing tools in collaboration with key local stakeholders foster cultural appropriateness.
 - Whether it is a self-assessment or an external evaluation, evaluators must be aware of their own cultural biases and reactions, be attentive to reactions generated by the evaluation, and modify terminology and methods accordingly.
-

Guideline 4: Using a shared framework to situate evaluations

Program evaluation questions and findings should be situated within a flexible common framework combining the CBR Matrix and the CBR Principles.

- CBR evaluation should be situated within a shared framework: it can mostly be used to define evaluation questions and to report evaluation findings. Other potential uses include clarifying potential gaps between what the program aims to achieve and is doing, developing data collection tools, identifying desirable outcomes, and structuring data analysis.
 - Further discussions among representatives of the CBR community are required to finalize this common framework. In the meantime, CBR evaluators should combine the CBR Matrix (ILO, UNESCO, & WHO, 2004b) and the CBR principles (WHO, UNESCO, ILO, & IDDC, 2010) in a flexible way and share their experience.
 - ✓ A shared framework for CBR evaluation is proposed in Figure 6.1. Evaluators should solely choose the elements that are relevant to their situation: one or more development area(s) of the CBR Matrix can be associated with one or more CBR Principle(s). Not all the cells should be filled in, only those that are relevant and match the evaluation focus. Words and formats can be changed to suit local context. In some instances, a simplified version of the framework can be used (Figure 6.2 for example), or the elements included in the framework may be considered in a relaxed discussion with local stakeholders.
 - ✓ This entails that a program evaluation clearly states which development areas (CBR elements) and which CBR principles were evaluated. For example, one could report on: How and to what extent has this program contributed to increasing the participation of people with disabilities in recreation, leisure and sports? How and to what extent has this program facilitated the inclusion of people with disabilities in mainstream primary education? Are the health promotion services provided to all groups without discrimination?
 - Other elements can be evaluated and be positioned in the 'other' column, these include: 1) program relevance, 2) process, 3) desirable and unintended outcomes for people with disabilities, families, & other community members, outcomes on policies or infrastructures, 4) costs, 5) quality of life of people with disabilities and their families, 6) external support, 7) strengths, 8) weaknesses, 9) opportunities, and 10) threats.
-

Guideline 5: Being inclusive of all voices during data collection
The perspectives of all relevant stakeholders should be included as data collection sources.

- Discussions with key local representatives help to determine whose perspective should be sought. This should include people with a range of disabilities, from different age groups, genders, races, ethnicities and religions, and representatives playing different roles such as beneficiaries, families, staff, partners, governments, donors and other community members. Those least often heard or who are most marginalized should express their opinions.
 - Conditions for participation should enable all to share their perspectives freely: access to meeting, meeting format and language, environment, tools used, and power dynamics. Innovation may be needed for the most disempowered to share their thoughts.
 - Resources available must be taken into consideration, and thus, those most affected by the program should be prioritized.
-

Guideline 6: Favouring mixed methods
Mixed methods should be strongly considered when planning data collection.

- Mixed methods generally enable evaluators to draw a comprehensive picture as they include both qualitative and quantitative data collection methods. For example, one may use qualitative data to set priorities as to which quantitative data will be collected. This may involve determining the most important program outcomes through discussion groups or semi-structured interviews, and then rating these outcomes on a scale to establish the extent to which they have been achieved.
 - The qualitative component is more likely to facilitate participation, imbue meaning to the process, identify unexpected outcomes, and provide a rich understanding of how a program operates and the changes it can bring.
 - The quantitative component provides data on the numbers affected by a program, and the magnitude of changes following participation.
 - In some situations, qualitative or quantitative methods alone may be better suited. Evaluators should consider which methodology suits evaluation objectives and available resources.
-

Guideline 7: Favouring participatory tools to collect data
Participatory tools should be strongly considered when planning data collection.

- These interactive tools and techniques generally use visuals and active listening to support group exercises designed to gather, organize or prioritize information. They facilitate general participation, while being especially helpful for children, as well as people with communication disabilities, with minimal formal schooling, or who are marginalized.
 - Specific tools could be proposed for all CBR programs, although evaluators need to decide which are relevant to the situation and how they need to be adapted to the local context.
 - Accessible resources for participatory tools and techniques include:
 - ✓ SAS² handbook for Participatory Action Research and evaluation (Chevalier & Buckles, 2013a). Examples: Timeline, Problem tree, Free list and pile sort, Resource mapping.
http://www.sas2.net/sites/default/files/sites/all/files/manager/Toolkit_En_March7_2013-S.pdf
 - ✓ Most Significant Change technique (Davis & Dart, 2005).
<http://www.mande.co.uk/docs/MSCGuide.pdf>
 - ✓ Outcome Mapping facilitation manual (Earl, Carden & Smutylo, 2001).
http://www.outcomemapping.ca/download.php?file=/resource/files/OM_English_final.pdf
-

Guideline 8: Using tools that closely fit the purpose
Data collection tools should be selected or developed according to maximal goodness of fit.

- Evaluators should draw from a broad range of tools to collect information: discussion groups, observations, individual interviews, review of program documents, written surveys or questionnaires, individual assessments, review of statistics, checklists, Photovoice or other strategies using drawings, letters or participatory tools. The use of more than one tool is beneficial for data triangulation.
 - Tools may be developed for a specific context (e.g. Community Attitudes checklist developed for and with the local community) or for use across programs (e.g. Quality of Life scale validated through research). Both context-specific and universal tools can be relevant, and may be used on their own or together. Context-specific tools are developed considering the context, information needs, local culture, and intended use of the results. Universal tools facilitate comparisons and lobbying on the international scene and may need to be adapted to the local context.
 - Evaluators should opt for fit for purpose: availability of tools that match information needs, intended uses for the results, whether a tool has been validated in a similar context, languages in which the tool is available, resources required and available (e.g. time, skills), fit with local culture, transferability to the local community and its leaders, potential for leadership by people with disabilities during data collection and analysis, and personal preference. Discussions with local representatives help to determine maximal goodness of fit.
-

Guideline 9: Alleviating the impact of linguistic differences
Strategies should be used to alleviate the impact of linguistic differences on participation and validity.

- Potential strategies include: 1) using translators who belong to the local culture, are as neutral as possible, and have some understanding of CBR, 2) training local native speakers to collect data, 3) learning the local language, 4) using visual tools or communication aids, 5) triangulating data with field observations, 6) being attentive to nonverbal cues, 7) audio-recording, transcription and translation when appropriate.
 - No single strategy can be effective and sufficient in all situations. Discussions with local representatives help to determine which best suit the local culture and evaluation context.
-

Guideline 10: Combining universal and context-specific indicators
Relevant universal and context-specific indicators should be chosen to reveal meaningful and important information about a program and its impact.

- Universal indicators coming from a bank of ready-to-use CBR indicators facilitate CBR lobbying on the international stage. They are useful to measure change on desirable outcomes that are common across many CBR programs (e.g. number of children with disabilities enrolled in primary school). Care must be taken to ensure that they are appropriate for the local reality. Discussions with local representatives help to determine which could be used. Alone, they are unlikely to yield the full picture.
 - Context-specific indicators are essential to capture a program's specificities and the context in which it is implemented (e.g. % of farmers who employ disabled workers). Often, they can better identify unanticipated program outcomes and impacts. These indicators should be developed locally, in collaboration with local stakeholders.
-

6.2.1 Guideline 1: Participatory evaluation process. The importance of striving for participatory CBR evaluation processes was highlighted in all three phases of this doctoral research. Although it was not emphasized in the systematic review on CBR evaluation, evaluation theorists refer to it as critical to enhance evaluation acceptability and impact (Chevalier & Buckles, 2013a; Fetterman & Wandersman, 2005; Green & Kreuter, 2005; Patton, 2012). On this matter, the field study revealed that evaluators should engage in egalitarian and non-judgemental relationships, respect local pace and clarify expectations to build sustainable partnerships and foster active engagement in evaluation activities (Grandisson, Thibeault, et al., 2014). The experts consultation validated the necessity for CBR evaluation to be participatory: 92% of the panel agreed that CBR evaluators should closely collaborate with key local stakeholders throughout the entire evaluation process to foster use of evaluation findings, and ensure an appropriate match between methods and community profile (Grandisson et al., 2015). Experts emphasized the necessity for evaluation decisions to be made by those most affected, including people with disabilities. This reflects CBR philosophy, as participation of disabled community members is a core principle of sound CBR program planning and implementation: these programs should be implemented for, by, and with people with disabilities (ILO, UNESCO, & WHO, 2004b; WHO, UNESCO, ILO, & IDDC, 2010). This is also congruent with Mertens' (2009) recommendation that disadvantaged individuals should take part in the definition of the evaluation's focus and questions. It is thus crucial for CBR evaluators to enable key local stakeholders to participate actively in CBR evaluation.

6.2.2 Guideline 2: Empowering evaluation process. Findings from the three phases of this doctoral research indicate that a CBR program evaluation should strive to be empowering, to give further control to key local stakeholders during and after an evaluation process. Although

only one article in the systematic review on CBR program evaluation specifically mentioned this (Boyce & Ballantyne, 2000), empowerment is crucial to CBR (WHO, UNESCO, ILO, & IDDC, 2010). Local stakeholders involved in the field study widely appreciated capacity building efforts: they liked how the evaluators created a learning climate conducive to sharing experiences, transferring knowledge, and training them to use participatory tools in a sustainable manner. (Grandisson, Thibeault, et al., 2014). Ninety-four percent of the expert panel agreed it should be a key characteristic of sound CBR evaluation (Grandisson et al., 2015).

Fetterman and Wandersman (2005) provide further directions regarding how to conduct empowering evaluations. For example, they suggest fostering democratic participation where everyone has an opportunity to share their perspectives, fostering a reflective evaluative culture, generating data enabling programs to be accountable to a range of audiences, and attempting to make positive change in people's lives, including the lives of those who are typically disadvantaged. In the field study, informal capacity building strategies, such as sharing tools and experiences as needs arose and gradually delegating evaluation roles, were more effective than a workshop. Experts involved in Phase 3 indicated that empowerment efforts may focus on those most directly affected by the results. They suggested strategies to give greater control to local stakeholders during and after an evaluation: training local data collectors, making recommendations associated with the program's monitoring tools and activities, and sharing findings in a way that empowers local stakeholders. All experts agreed that findings should be shared locally and with other audiences when appropriate to advance knowledge and contribute to CBR advocacy. Promoting use of evaluation findings may also contribute to empowerment. It emerged as critical in the literature review (Fetterman & Wandersmans, 2005; Patton, 2012; Price & Kuipers, 2000; WHO & IDC, 1996; WHO, ILO, UNESCO, & IDDC, 2010; Zhao &

Kwok, 1999) and 94% of the experts consulted thought that actions should always follow CBR evaluation. On that matter, Kuipers and Harknett (2008) recommended that CBR evaluation should include cycles of reflection and action. South African program managers illustrated this well when they requested the evaluation report quickly to make changes before the next evaluation round. In summary, CBR evaluators need to be creative and use numerous strategies to empower key local stakeholders.

6.2.3 Guideline 3: Embracing cultural diversity in the evaluation process. Given the wide range of contexts in which CBR programs are implemented, this issue is particularly critical to address. When different cultures meet, Mertens (2009) suggests that questions of power and privilege be addressed after trust has been built, while Fetterman and Wandersman (2005) highlight the value of community knowledge. During the field study in South Africa, evaluators quickly realized the necessity to be sensitive to the impact of potential cultural differences, including diverging views on what is considered a disability and on the implications of labeling (Grandisson, Thibeault, et al., 2014). Experts also underlined the critical importance of respecting cultural differences: a respondent wanted it added as a criterion to the initial model, and 94% agreed that evaluators should pay attention to the impact of cultural differences and adapt as needed (Grandisson et al., 2015). To overcome potential drawbacks, authors suggest that ongoing self-reflection and self-critique of one's own biases, and recognition of other views' legitimacy, are key (Gray & McPherson, 2005; Ross, 2010). The experience in South Africa confirmed that evaluators must be aware of their own perception of disability, be sensitive to reactions induced by the evaluation, and engage in respectful discussions to understand their partners' vision. Thus, embracing cultural diversity requires holding open discussions with local representatives, and being self-critical, open-minded, sensitive and flexible. This is essential for

all to feel respected and confident that they can share their true feelings and beliefs and, as a consequence, for the evaluation results to be trusted.

6.2.4 Guideline 4: Using a shared framework to situate evaluations. A wide range of frameworks has been proposed for CBR program evaluation: 13 were retrieved in the systematic review (Grandisson, Hébert, et al., 2014). As a consequence, outcomes vary greatly and findings from different sources are hard to combine into a cohesive evidence base for CBR (Finkenflugel et al., 2005). In the third phase of this study, experts agreed on the value of a shared framework for CBR evaluation (Grandisson et al., 2015). Most importantly, this framework can provide a clear picture of what CBR aims to achieve and could be used to define evaluation questions and to situate findings when reporting results. Experts explained that this could in turn contribute to facilitating cross comparisons between CBR programs, collaboration in building CBR's evidence base, and advocacy work using this evidence. The literature review also indicated that a shared framework could help select and develop data collection tools, identify outcome measures, structure data analysis and reveal potential gaps between a program's aims and actual impact (Chen, 2005; Finkenflugel et al., 2008; Thomas, 2011). The experience in South Africa supported this since discussions around the common framework helped to define a shared language and understanding, facilitated the choice of outcome measures, fostered evaluative thinking, and helped to identify gaps between what the NGO wishes to accomplish and the reality (Grandisson, Thibeault, et al., 2014). Thus, findings from this doctoral study strongly support the necessity for the CBR community to agree on a flexible shared framework to be used across all CBR program evaluations.

Because none of the available frameworks appeared to have yielded such consensus, and because none appeared sufficiently clear, comprehensive, applicable, and representative of CBR

values and contexts, a framework combining the CBR Matrix (ILO, UNESCO, & IDDC, 2004b) and the Evaluation Hierarchy (Rossi et al., 2004) was developed at the end of Phase 1. Although it worked well in the field study, the expert panel did not retain this option. Instead, they reached consensus on a shared framework for CBR evaluation combining the CBR Matrix (ILO, UNESCO & WHO, 2004b) and the CBR Principles (WHO, UNESCO, ILO, & IDDC, 2010). They liked this option's comprehensiveness and potential to capture impact. Although some panellists were concerned about its complexity, others thought that by using it as a menu, i.e. selecting only the components that are relevant to their situation, this framework could be both useful and manageable. Yet, because of limitations associated with Delphi studies with two pre-defined rounds, not all the suggestions received could be fully explored. For example, one expert commented that the framework purpose was unclear, and another that the CBR Principles were too concise. Hence, further discussions among CBR community representatives could be beneficial to refine this shared framework. The main concerns were addressed by: 1) clarifying why and how it could be used, 2) adding non-discrimination to the CBR Principles, 3) dividing the principles into those related to changes the program brings (i.e. program outcomes) and to how the program operates (i.e. program implementation), and 4) providing short explanations for each principle to facilitate use.

Both the experience in South Africa and the experts consultation indicated that the framework's flexibility was essential (Grandisson, Thibeault, et al., 2014; Grandisson, Hébert, et al., 2014). These two studies provided indications as to how that could be achieved: local representatives may choose solely the components that are relevant to them and may change the labels of some of the categories; there may be space for information that does not fit; and the components included in the framework may be simply discussed with local representatives. To

address this, the author added space for information that does not fit in the framework, designed a simplified version of the framework, and proposed different ways to use the framework to accommodate local communities.

Figure 6.1 presents the improved framework. Follows a simplified version in Figure 6.2 to offer a second, simpler option. The latter focuses on the five components of the CBR Matrix (ILO, UNESCO & WHO, 2004b) and does not provide CBR Principles' definitions (WHO, UNESCO, ILO, & IDDC, 2010). In addition, insights from the literature review and experts' suggestions were used to generate a list of other elements that may be evaluated, which may not readily fit in the framework. This list is available in Guideline 4 and is purposely left broad to allow space to generate other evaluation questions locally.

	Changes the Program Brings			How the Program Operates				Other
	Participation	Inclusion	Autonomy	Non-discrimination	Empowerment	Multisectoral collaboration	Sustainability	
	Access and take part in activities	Take part in mainstream activities as equal group members	Develop and use their full potential	Regardless of disability, gender, age, religion, ethnicity, & socioeconomic status	People with disabilities taking decisions, being active contributors, & assuming leadership roles	In partnership with key stakeholders from relevant sector(s) and at different levels	Using resources optimally, prioritizing local resources, not depending much on external resources	
HEALTH Promotion Prevention Medical care Rehabilitation Assistive devices								
EDUCATION Early childhood Primary Secondary & higher Non-formal Lifelong learning								
LIVELIHOOD Skills development Self-employment Wage employment Financial services Social protection								
SOCIAL Personal assistance Rel., marriage & family Culture & arts Recreat., leisure & sports Justice								
EMPOWERMENT Advocacy & com. Community mobiliz. Political participation Self-help groups DPOs								

Figure 6.1. Shared framework for CBR evaluation. *Note.* Includes CBR Matrix (ILO, UNESCO, & WHO, 2004a) and CBR Principles (WHO, UNESCO, ILO, & IDDC, 2010).

	Changes the Program Brings			How the Program Operates				Other
	Participation	Inclusion	Autonomy	Non-discrimination	Empowerment	Multisectoral collaboration	Sustainability	
Health								
Education								
Livelihood								
Social								
Empowerment								

Figure 6.2. Simplified shared framework for CBR evaluation. *Note.* Includes CBR Matrix (ILO, UNESCO, & WHO, 2004a) and CBR Principles (WHO, UNESCO, ILO, & IDDC, 2010)

6.2.5 Guideline 5: Being inclusive of all voices during data collection. Findings from all three phases of this doctoral study strongly indicate that sound CBR methodologies should enable representatives from all groups that may be affected by the program or the evaluation results to express their opinions freely. This conclusion first emerged in the literature review (Grandisson, Hébert, et al., 2014), and was validated in the two following phases (Grandisson, Thibeault, et al., 2014; Grandisson et al., 2015). This echoes the importance given by Mertens (2009) and Fetterman and Wandersman (2005) to reaching disadvantaged community members. Similarly, findings from the systematic review highlight that people with disabilities should have the opportunity to express their thoughts and that multiple data sources

should be triangulated (Kuipers & Harknett, 2008). For example, in the field study, program representatives from the South African NGO held diverging views on the challenges associated with foetal alcohol spectrum disorder (FASD): staff struggled to deal with behavioural and developmental consequences of the condition while managers deemed all FASD labeling as detrimental and preferred not to adapt the program to its specificities. As a consequence, triangulating data collected from both groups and from observing program activities proved essential to reach accurate conclusions. Furthermore, providing parents of children with FASD with an opportunity to share their ideas appeared to boost their self-confidence and feeling of belonging to the program, while yielding real-life examples of the program impact in children's homes. In the last phase of this study, 83% of the expert panel believed inclusiveness was one of the three most important criteria of sound CBR program evaluation out of a list of seven. Panellists pointed to the necessity to include representatives from all disability and age groups, as well as community members who may be indirectly affected. In line with Phases 1 and 2 findings, one panellist suggested that giving a voice to individuals who are least often heard is a priority. In addition, one indicated that inviting individuals to participate is not sufficient; data collection conditions and strategies should enable all to share their perspectives freely. This had also been discussed in the field study as the physical environment, the climate in which data collection took place, and the types of tools used all contributed to engagement in evaluation activities. Hence, my findings suggest that evaluators should invite those who can be most affected by the CBR program to participate, and ensure that marginalized groups have a chance to contribute and that data collection conditions enable all to share their thoughts freely.

6.2.6 Guideline 6: Favouring mixed methods. As mentioned in the systematic review, qualitative methods have been used extensively in CBR and remain relevant (Sharma, 2004;

WHO & IDC, 1996). But, nonetheless, some authors called for the integration of quantitative and mixed methods to provide a stronger case for CBR advocacy (Cornielje et al., 2008; Wirz & Thomas, 2002; Zhao & Kwok, 1999). This position clearly reflects best evaluative practices and the experts' opinions obtained in Phase 3: mixed methods, or at least the combination of multiple methods, generally enable evaluators to better grasp complex realities and respond to all stakeholders' information needs, including beneficiaries', program managers', donors', and governments' (Grandisson et al., 2015; Kuipers & Harknett, 2008; Mertens, 2009; Fetterman & Wandersman, 2005). In Phase 2, parents, staff members and managers first identified desirable and unintended outcomes of the program through qualitative methods. They then rated the program's performance on these outcomes and shared stories to support their ratings. This strategy led to the identification of outcomes that would not have arisen otherwise (Grandisson, Thibeault, et al., 2014). Qualitative methods also helped to identify the program's strengths and challenges, while quantitative ratings completed the picture and facilitated comparisons over time and the fulfilment of donors' expectations. Although 76% of expert panel members concurred that mixed methods should generally be favoured, the group insisted that methodological decisions should always be founded on fit for purpose (Grandisson et al., 2015). Thus, qualitative or quantitative methods alone may be better suited to very specific evaluation questions or evaluation contexts that call for lesser complexity.

6.2.7 Guideline 7: Favouring participatory tools to collect data. Participatory tools and techniques, such as those developed by Chevalier and Buckles (2013a) were found to be exceptionally relevant for CBR program evaluation. Although only two of the 22 documents included in the systematic review had specifically indicated that they could be suitable for CBR (Kuipers & Harknett, 2008; Sharma, 2004), both the field study and the experts consultation

validated that CBR evaluators should strongly consider using participatory tools to facilitate active engagement of all groups in evaluation activities, and especially of children, people with communication disabilities or who are marginalized (Grandisson, Thibeault, et al., 2014; Grandisson et al., 2015). These tools were highly effective during the evaluation of the South African program, as they fostered the active engagement of all groups, from tertiary educated individuals to others with limited or no formal schooling. Not only did they enable all to share their perspectives, but they also appeared to boost their confidence in the evaluation process, and motivate all groups to contribute actively. Evaluation results were consequently better understood and trusted by all groups, enhancing the potential for local stakeholders to take useful actions aligned with evaluation findings. In Phase 3, 88% of the experts indicated they had used them and 100% thought they should be strongly considered. Some added that these tools could be empowering for the local community. Thus, findings from this doctoral study suggest that participatory tools could become an integral part of most CBR program evaluations.

6.2.8 Guideline 8: Using tools that closely fit the purpose. Choosing between context-specific and universal tools to collect data is an important methodological decision. Insufficient directions to inform that choice were found in the literature: some authors developed a tool for a specific context and acknowledged that their process could be replicated in other contexts (Adeoye et al., 2009; Pal & Chaudhury, 1998), while others suggested that Quality of Life scales, standard flow charts or standard tables may be used across programs (Mannan & Turnbull, 2007; Velema et al., 2008, Zhao & Kwok, 1999). In the field study, the authors struggled to identify a universal tool evaluating children's performance in terms of confidence, development and school readiness suited to the local context (Grandisson, Thibeault, et al., 2014). Tools evaluating such outcomes do exist but, given the community's limited resources, they require excessive external

support to be of sustainable use. The experts consulted resolved the dilemma in Phase 3: 81% believed that both context-specific and universal data collection tools can be relevant and may be used on their own or together, depending on the situation (Grandisson et al., 2015). They explained that maximal goodness of fit is what really matters: evaluators should consider whether tools available meet their information needs, fit community profile, offer sound psychometric properties, are available in the local language, and require reasonable resources. To further determine fit for purpose, experts also indicated that evaluators should consult local representatives, and consider who may use evaluation findings and how. They suggested that standards tools may need to be adapted to the local context. More recently, Lukersmith and colleagues (2013) reviewed the literature on monitoring and evaluation tools for CBR and indicated that, out of the 14 tools retrieved, none had been used more than once. The authors suggested that standard evaluation tools for CBR could be beneficial if they are carefully selected considering information needs, program goals, level of skills required, validation with the population with whom they are to be used, and potential for people with disabilities' leadership. In summary, no tool can be used in all contexts; evaluators should base decisions on maximal goodness of fit.

6.2.9 Guideline 9: Alleviating the impact of linguistic differences. This issue first emerged in the field study when the evaluators (MG and RT) did not speak the local language and relied on a translator to include the perspectives of parents of children with FASD (Grandisson, Thibeault, et al., 2014). In this case, it facilitated their participation, as they were eager to share their stories in Afrikaans and forgot to wait for the translations. Although audio-recording could have helped to ensure that no information was missed, the evaluators did not use it because they felt it could have intimidated participants. All the experts consulted in Phase 3

agreed that evaluators should use strategies to alleviate the impact of linguistic differences on validity and participation and pointed to a range of strategies (Grandisson et al., 2015). Among them is learning the local language. Although this might appear ideal, the author feels that evaluators need to achieve a good level of proficiency in the new language if the experience is to be positive. Consequently, imposing the acquisition of a language could limit external evaluations in languages spoken in fewer or more remote geographical areas. Experts made other suggestions, including training local data collectors, using visual tools or communication aids, triangulating data with field observations, and paying attention to non-verbal cues such as gestures and facial expressions. While using strategies to alleviate the impact of linguistic differences emerged as paramount, the author believes that no single strategy can be applied to all contexts and thus, evaluators should discuss with local representatives to determine which ones best suit the context at hand.

6.2.10 Guideline 10: Combining universal and context-specific indicators. In Phase 1, authors held diverging opinions on the use of indicators to reveal meaningful and important information about a program and its impact (Grandisson, Hébert, et al., 2014). Some advocated using locally generated ones to ensure they represent the most significant changes in local stakeholders' perspectives (Adeoye et al., 2011; Chung et al., 2011), while others proposed to develop a list of universal CBR indicators to be used across programs to facilitate exchanges and the creation of a more solid evidence base for CBR effectiveness (Wirz & Thomas, 2002). The use of both in the field study was positive: the desirable outcomes from the CBR Guidelines were used to generate universal indicators, but were complemented with locally generated ones capturing the most important differences associated with children's participation in the program (i.e. gaining confidence) (Grandisson, Thibeault, et al., 2014). In Phase 3, 90% of the expert

panel believed a CBR program evaluation should ideally combine universal indicators to facilitate lobbying and cross-comparisons, with context-specific ones to foster local ownership and reflect local specificities (Grandisson et al., 2015). WHO launched a call for proposals in the summer of 2014 to develop a list of universal CBR indicators. To be congruent with best practices, the author recommends that a simple procedure to generate context-specific indicators locally should accompany this list.

6.3 Best Practice Model for CBR Program Evaluation

A best practice model for CBR program evaluation summarizes and organizes the guidelines into processes, frameworks, and methods (Figure 6.3). Evaluators are invited to look at this model before, during and after a CBR program evaluation in order to make sound decisions regarding how to carry the evaluation and to reflect on the evaluation process afterwards. The upper section of the model represents the three key features of sound CBR evaluation processes discussed in Guidelines 1 to 3. An eight-step process to facilitate evaluation implementation follows. Stars in the figure call attention to three critical steps to emphasize according to the results of this doctoral research. In the middle section, Guideline 4 clarifies best practices regarding the use of frameworks in CBR evaluation. The shared framework proposed is intended to provide a common language when defining evaluation questions and reporting findings from a CBR program evaluation: it focuses on what is evaluated. In the lower section of the model, evaluators are invited to consider Guidelines 5 to 10 for guidance on suitable methods for CBR program evaluation. These should enable them to make sound decisions about methodologies, data collection sources and tools, as well as indicators. The three categories follow a logical order: evaluators should first familiarize themselves with key process features, then situate evaluations within a framework, and only then develop methods. Key process features will guide how frameworks and methods should be selected and planned (e.g. ensuring

key local stakeholders contribute to decisions). Similarly, the framework chosen and where the evaluation fits within this framework influences choice and development of data collection tools.

In regard to designing and facilitating sound CBR evaluation processes, the CBR program evaluation model highlights that close collaboration is required at all evaluation stages to establish and adjust local stakeholders' degree of involvement, to determine how and to what extent the local community will be empowered, and to alleviate the impact of potential cultural differences. The three critical steps, namely engaging stakeholders, sharing findings and promoting use of findings, appear strongly congruent with the key features of the evaluation process. Thus, the author believes that paying attention to these steps could help ensure an evaluation is participatory, empowering and embracing cultural diversity. As for the framework in which CBR program evaluation should be situated, using the common framework suggested should facilitate the building of a more solid and cohesive evidence base for CBR, congruent with its major principles. Yet, more discussion is required among CBR community representatives to finalize this shared framework and ensure it remains easy to use and adaptable. In relation to methods, given the considerable variability in CBR contexts, evaluation resources available, and possible uses of evaluation results, resorting to a single standard CBR methodology across all programs appears undesirable. The model recommends six characteristics to take into account for sound methodological choices that enable all concerned to participate actively, yield an accurate and comprehensive picture, and foster the generation of data that can be used for program improvement and accountability.

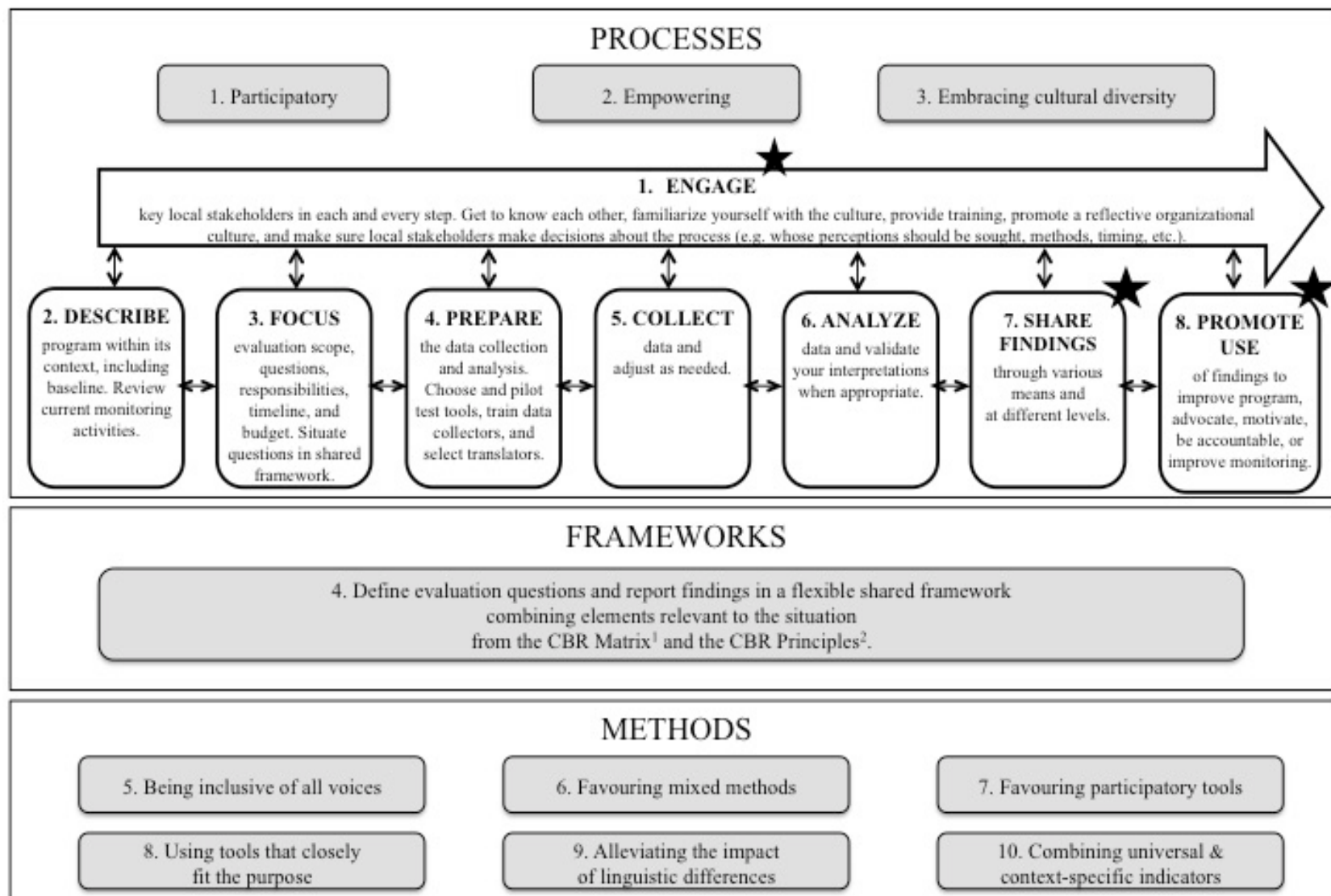


Figure 6.3. Best practice model for CBR program evaluation. *Note.* Eight steps first presented in Grandisson et al. (2015). Stars call attention to critical steps of sound CBR program evaluation processes.

1: ILO, UNESCO, & WHO (2004a)

2: WHO, UNESCO, ILO, & IDDC (2010).

6.4 Conclusion

This doctoral thesis filled a knowledge gap in relation to best practices in CBR program evaluation. It successfully defined key features of sound CBR evaluation processes, critical steps to emphasize and key elements that should influence methodological choices. In addition, a framework based on the CBR Matrix (ILO, UNESCO, & WHO, 2004a) and the CBR Principles (WHO, UNESCO, ILO, & IDDC, 2010) was developed to facilitate exchanges between programs and the building of a more solid and cohesive evidence base for CBR. Although there is no single CBR evaluation method that can be applied to all situations, the best practice guidelines and model offered in this chapter will provide much-needed guidance and confidence to those evaluating CBR programs. They provide clear directions on how to conduct rigorous, participatory, empowering, and inclusive CBR program evaluation, and will undoubtedly contribute to improving CBR program evaluation practices. Three aspirations stand out and will hopefully be remembered by all those evaluating CBR programs: 1) giving a voice and control to the most affected groups, including people with disabilities, 2) embracing the challenge of diversity by adapting CBR evaluation to cultures and languages, and by ensuring no one is left behind by a CBR program, and 3) fostering the use of processes and findings through a rigorous, collaborative and empowering approach.

The methodology designed to prepare the guidelines followed gold standards of guidelines development (AGREE Next Step Consortium, 2009): the rigorous three-phase process enabled the author to draw the best from the available literature and stakeholders' views, which in turn led to the guidelines' comprehensiveness, clarity and applicability, and the promotion of stakeholders' participation in their development. The guidelines were systematically developed thorough a systematic literature review (Grandisson, Hébert, et al., 2014), and were refined and validated in the field with one CBR program (Grandisson,

Thibeault, et al., 2014) and with a panel of CBR experts (Grandisson et al., 2015). Discussions on the evidence underlying each guideline testify to their rigour (AGREE Next Step Consortium, 2009). In respect to the guidelines' comprehensiveness, more than 10 guidelines could have been developed to reflect all the suggestions received and the insights gained. Yet, the author chose to focus on the strongest points to keep the guidelines succinct, clear, and accessible. This does not mean that other elements were disregarded; rather they were integrated into the 10 guidelines. For example, the need for flexibility is reflected in Guidelines 1, 2, 4 and 9: implementation suggestions clarify that stakeholders' degree of participation and empowerment will vary, offer different ways to use to the common framework, and specify that no single strategy can effectively alleviate the impact of linguistic differences in all scenarios. In addition, although it was tempting to encompass both CBR monitoring and program evaluation in these guidelines, I chose to focus on program evaluation because I wished to focus on how to analyze CBR programs' worth and the conditions under which these programs are most effective. The context of my doctoral thesis also meant that I needed to concentrate on one theme to ensure that I would explore it fully and that I would be able to advance knowledge significantly within the time frame and resources available.

Congruent with the importance of participation common to CBR, evaluation, and guidelines development (AGREE Next Step Consortium, 2009; WHO, UNESCO, ILO, & IDDC, 2010; Green & Kreuter, 2005; Fetterman & Wandersman, 2005; Patton, 2012), key stakeholders shared their perspectives on best evaluative practices in CBR to refine and clarify the model generated, and to foster its acceptability and applicability. Parents of children with FASD, program managers and program staff provided feedback on the South African evaluation in Phase 2. In addition, 42 CBR experts shared their opinions and reached consensus on all ten

guidelines for best evaluative practices in Phase 3. More experts from low- and middle-income countries directly involved in CBR programs on a day-to-day basis would ideally have been recruited in the consultation. Although snowball sampling upon initial contact specifically aimed at recruiting more panellists with these characteristics, phone calls to present the project or contacts initiated by panel members who knew these individuals personally could have further promoted their participation. Yet, the panel is highly credible: it includes very experienced members and leaders of the CBR community from a wide range of backgrounds and geographical areas, five of whom had a disability.

This doctoral research process successfully advanced knowledge as the candidate systematically developed and tested a model and guidelines on best practices in CBR program evaluation. Future studies could complement this thesis and further enhance the guidelines' applicability by carrying external validation and field-testing in other CBR contexts. Other desirable developments to facilitate the guidelines' implementation include a CBR program evaluation manual, decision-aids and reflective tools to use when designing or conducting a CBR program evaluation, flexible data collection tools for CBR, a list of universal CBR indicators, a simple procedure to generate context-specific indicators locally, and training initiatives. In the mean time, CBR program stakeholders, evaluators, and researchers can rely on much clearer directions regarding best practices in CBR program evaluation.

General Conclusion

While the necessity to evaluate community-based rehabilitation (CBR) programs is recognized (WHO, UNESCO, ILO, & IDDC, 2010), those attempting to evaluate CBR programs encounter many challenges associated with the multisectoral nature of this community development strategy, the limited resources available, and the range of cultural contexts in which CBR is implemented. Before this doctoral thesis, insufficient directions were offered to overcome these and carry rigorous CBR program evaluations corresponding to sound evaluative practices, CBR values, and CBR realities (Grandisson, Hébert, et al., 2014). Although authors had made a range of suggestions regarding the desirable features of CBR program evaluation, no comprehensive, rigorous, and applicable guidelines were available. This thesis fills this knowledge gap by defining key features of best practices in CBR program evaluation and by providing much-needed practice guidelines on this topic.

A rigorous three-phase research process enabled me to systematically develop the guidelines, validate and refine them. Firstly, a thorough literature review and analysis allowed the identification of potential features and steps of sound evaluative practices in CBR, while helping to develop a framework to situate evaluation questions and findings. This was critical to ensure the guidelines' congruence with CBR philosophy and sound evaluative practices. Subsequently, a South African CBR program was evaluated and the process appraised to learn about suitable strategies for CBR program evaluation. This field study honed the applicability of the guidelines and yielded a deeper understanding of the challenges and strategies associated with CBR program evaluation. In the third and last phase, 42 CBR experts from a wide range of perspectives shared their opinions and reached consensus on best evaluative practices in CBR. This Delphi study validated and refined the best practice guidelines initially developed in terms of clarity and comprehensiveness, while promoting their acceptability in the CBR community.

Findings from this study emphasize the importance for key local stakeholders to make decisions regarding the evaluation process, the necessity to use creative strategies to empower them through the process, and the need to give a voice to people who may be marginalized because of their disability, gender, age group, culture, ethnicity, or religion. Thus, the guidelines reinforce that a CBR program evaluation must remain strongly aligned with the core principles of this strategy, namely inclusion, non-discrimination, participation and empowerment. Surprisingly, the CBR evaluation literature did not emphasize this, especially not the importance of conducting empowering program evaluations (Grandisson, Hébert, et al., 2014).

The 10 practice guidelines developed provide clear and indispensable guidance on how to conduct CBR program evaluation. Three of the guidelines are associated with key features of sound CBR program evaluation processes: these indicate that a CBR program evaluation should be as participatory and empowering as possible, and should embrace the challenge of cultural diversity. This requires close collaboration with key local stakeholders throughout the entire program evaluation process, as they know best which strategies suit their setting. This also means that CBR program evaluation processes should be designed to empower key local stakeholders, including people with disabilities, and that evaluators should pay attention to the impact of cultural differences before, during and after evaluations, and adapt as needed. Regarding the use of frameworks, one guideline recommends situating program evaluation questions and findings within the flexible common framework developed in this thesis. This framework combines the CBR Matrix (ILO, UNESCO, & WHO, 2004b) and the CBR Principles (WHO, UNESCO, ILO, & IDDC, 2010), and gained expert consensus. This should facilitate exchanges between programs and foster the building of a more cohesive evidence base for CBR. Since no single methodology can be relevant to all CBR and evaluation contexts, six guidelines

suggest key features to consider when making methodological decisions: being inclusive of all voices, favouring mixed methods, favouring participatory tools, using tools that closely fit the purpose, alleviating the impact of linguistic differences, and combining universal and context-specific indicators. In other words, the guidelines call for efforts to include the perspectives of all stakeholders as data collection sources. They also indicate that evaluators should strongly consider using mixed methods and participatory tools to foster the gathering of a valid and comprehensive picture of the program, and to facilitate engagement in evaluation activities. Nonetheless, one of the guidelines also emphasizes that data collection tools should be selected or developed considering maximal goodness of fit, reminding evaluators that mixed methods and participatory tools might not be relevant in all situations. Because of the wide range of linguistic contexts in which CBR programs are implemented and because of the inherent threat this poses to participation in evaluation activities and to the validity of the findings, one guideline indicates that evaluators should be creative and use diverse strategies to alleviate the impact of linguistic differences. Finally, the last guideline stresses that relevant universal and context-specific indicators should be chosen to reveal meaningful and important information about a program and its impact. As a consequence, although a list of universal CBR indicators could be useful to facilitate exchanges and cross-comparisons, it must be accompanied by a simple participatory procedure to generate context-specific indicators, which are meaningful to local stakeholders and capture local specificities.

By clarifying how CBR programs should be evaluated, the guidelines developed should foster accountability to beneficiaries, community members, governments and donors, and lead to the building of a more solid and cohesive evidence-base for this strategy. In turn, this should help scale-up CBR programs and ensure they contribute to empowering people with disabilities and to

further equalizing their opportunities to be healthy, be educated, earn a decent livelihood, and be genuinely included in their community's social life. The major strengths of this research process include rigour, field-testing in one CBR setting, stakeholders involvement, and consensus generation among a highly credible expert panel from a wide range of backgrounds and geographical areas. I now recommend external validation and field-testing in other CBR settings to further enhance the guidelines' clarity and applicability. This could be an excellent opportunity to create relevant practice scenarios to accompany the guidelines. More research is also needed to develop adaptable data collection tools aligned with this study's definition of best practices in CBR program evaluation. In addition, knowledge translation initiatives are required: these could include the development of a manual, decision-aids or reflective tools for CBR program evaluation, or online and in-person training opportunities.

In line with Participatory Action Research (PAR), findings were disseminated to the participants. In the field study, program evaluation findings were shared with the program's managers through a meeting and an evaluation report. In addition, lessons learned on suitable program evaluation strategies can be found in a manuscript written in collaboration with a program representative (Grandisson, Thibeault, et al., 2014). These were also used to design future evaluation rounds carried by my supervisor (RT). As the project continues to unfold in South Africa, Rachel Thibeault will disseminate the findings more broadly with other participants in the Fall of 2015. As for the experts involved in the Delphi study, I sent them summary of findings from both consultation rounds and will send them the published article on the consultation.

The researcher's journal I have completed throughout my doctoral journey allows me to highlight some of the key events that influenced this research process and helped me progress.

First, the publication of the *CBR Guidelines* in December 2010 (WHO, UNESCO, ILO, & IDDC), shortly after I started my doctoral course work, quickly made me realize that insufficient guidance was available to conduct rigorous CBR program evaluation aligned with CBR values and realities. Then, the first field visit in South Africa in February 2011, before the actual data collection, helped me to better understand CBR program evaluation needs and context, while building trust with local representatives. As a doctoral candidate, I first through I needed to prove that I could bring in knowledge in order to be useful to them. In both field visits (2011, 2012), I was impressed by how my supervisor (RT) listened actively and let go to ensure key local stakeholders led the process, not us. These experiences enabled me to understand that community development projects will be most successful if I wear a facilitator's hat instead of an expert's hat, and if I concentrate on developing sustainable partnerships. My participation in two meetings on CBR monitoring and evaluation organized by the World Health Organization (WHO) also influenced the process and deepened my understanding of what was needed to improve evaluative practices in CBR. The meetings forced me to clarify my thesis' focus and my intended contribution, while assisting me in the identification of experts who could participate in the Delphi study planned for Phase 3. In addition, they helped me grasp how the knowledge generated in my thesis could be disseminated and hopefully used if a manual on CBR program evaluation was to be developed under WHO's leadership. For all these reasons, I now feel that I have progressed tremendously during my doctoral adventure: I now better understand the importance of truly listening to my partners and participants and the need to continuously review my objectives to ensure they remain clear and relevant. I also know that I value PAR particularly and will make efforts to foster meaningful changes for the communities involved in my research projects. I have gained the confidence and skills to carry responsible studies associated with

disability and community development. As a future professor in occupational therapy, I now feel better equipped to contribute to the building of more inclusive communities that promote the participation of all, regardless of their abilities, age, sex, race, ethnicity or socioeconomic status. Although I will not solely work on CBR, I will always attempt to adhere to its core principles of inclusion, non-discrimination, participation, and empowerment.

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Appendices

Appendix A: Publishers' Permissions to Include Articles

Authorization for article on systematic review (Chapter 3).

Marie Grandisson <>

To: permissions@informa.com

Hi,

I published an article with you in Disability & Rehabilitation Journal (2014). A systematic review on how to conduct evaluations in community-based rehabilitation. It is published open-access.

As I am a doctoral candidate, I wish to reuse the full article in my thesis (clearly acknowledging that it was first published in D & R). I believe the license with Informa already allows be to do that. My institution will deposit my thesis in an electronic depository (without passwords). Could you please confirm that this complies with Informa's rules and regulations?

I tried to do the authorization process with RightsLink, but they advised me to contact you directly to make sure that this is correct.

Sincere thanks,

Marie Grandisson

PhD Candidate, Rehabilitation Sciences

University of Ottawa

Legge, Malavika <>

To: Marie Grandisson <>

Hi Marie, while you DO have permission to reproduce the article in your thesis, we do not allow the open access sharing of the articles and our copyright policy does not permit the full article to be shared online in a non-password-protected manner.

Thanks and best wishes

Malavika

Malavika Legge Publishing Rights Manager

Informa healthcare

Marie Grandisson <>

To: "Legge, Malavika" <>

Dear Malavika Legge, Thank you for your email and confirming that I have permission to reuse my article in my thesis. I would like to reiterate that my article is published open-access, that I paid for the article to be accessible from everywhere in a non-password-protected manner. Hence, I believe I should have the right to use it in my thesis AND make it accessible according to my institution policy?

Thank you for considering this request as it is essential for my PhD.

Marie Grandisson

PhD Candidate, Rehabilitation Sciences

University of Ottawa

Legge, Malavika <>

To: Marie Grandisson <>

Sorry, Marie, I did not realise this earlier; if you paid Gold-OA fees in order for your final paper to be published as an OA paper, then yes, of course, you DO have permission to make the final article freely accessible (as long as this is for non-commercial purposes and as long as the article is not modified).

Thanks and best wishes

Malavika

Authorization for article on field study (Chapter 4).

Marie Grandisson <>

To: Maya Thomas <editor.dcid@gmail.com>

Dear editor,

I would like to re-use an article published in DCID journal as part of my doctoral dissertation, written as a series of articles, and which will be published online and in print format. Is it possible to obtain a written permission that I can re-use the material from the article below please? Published in 2014, issue 25 (1): Community-Based Rehabilitation Program Evaluations: Lessons Learned in the Field (55-71). Marie Grandisson, Rachel Thibeault, Michèle Hébert, Annie Templeton.

Many thanks,

Marie Grandisson

--

Marie Grandisson

PhD Candidate, Rehabilitation Sciences

University of Ottawa

Maya Thomas <editor.dcid@gmail.com>

To: Marie Grandisson <>

Dear Ms. Grandisson,

I had sent your request to our Chief Editor, who has agreed that you can re-use the article, but acknowledging DCIDJ as the source.

Regards

Vardhani

Authorization for article on experts consultation (Chapter 5).

From: Marie Grandisson [mailto:] Sent: 21 April 2015 18:15 To: Dalglish, Sandy
Subject: Re: Welcome to Taylor & Francis Production: Disability and Rehabilitation 1044030
Hello,
Thank you for your email.

I just tried calling you to clarify a few things before signing the agreement. I guess the time difference between UK and Canada means that I missed you Today. I will therefore try to write my questions here, and if you think they would be better answered by phone I will try again to call you tomorrow (Wednesday).

1. Do all 4 authors need to sign the contributors' form?

2. I am a PhD candidate and I will soon submit the final version of my thesis to the University of Ottawa (hopefully end of May 2015). The article mentioned in the copyright agreement is included in my thesis (is much less than half, maybe 1/6th of my thesis). All theses from the University of Ottawa are deposited in our university repository, which do not require passwords.

- From what I understand from the copyright agreement, it seems that I can include the final published version (would be early online then I guess) in my thesis (actual pdf when you download it on informa's website) with the permanent link to the article on informa's website since it constitutes less than half of the content of the thesis. Could you please confirm this and confirm that there is no embargo period for such reuse of the publication?

Of course, I would mention before the article: "This is the accepted version of the following article: (Expert consensus on Best Evaluative Practices in Community-Based Rehabilitation), which has been published in final form at (<http://dx.doi.org/10.3109/09638288.2015.1044030>)."

- If not, I guess I would need a separate agreement with Informa to include the accepted version the manuscript in my thesis?

Sincere thanks,

Marie Grandisson

On Wed, Apr 22, 2015 at 6:44 AM, Dalglish, Sandy <
Dear Marie,

> wrote:

As long as the article is cited you shall be able to include it.

Only 1 author needs to sign the copy right form.

Kind Regards,

Sandy Dalglish
Production Editor, Journals
Taylor & Francis

From: Marie Grandisson [mailto:] Sent: 22 April 2015 14:22
To: Dalglish, Sandy
Subject: Re: Welcome to Taylor & Francis Production: Disability and Rehabilitation 1044030

Dear Sandy,

Thank you for your message. Just to make sure, I can therefore include the final or early online pdf version of the article in my thesis (and not only the accepted version)?

I will send you the signed copyright form today or tomorrow.

Best regards,

Marie

From: Dalglish, Sandy <>
Date: Wed, Apr 22, 2015 at 10:27 AM
Subject: RE: Welcome to Taylor & Francis Production: Disability and Rehabilitation 1044030
To: Marie Grandisson < >

Yes as long as you state where it has come from.

Kind Regards,

Sandy Dalglish
Production Editor, Journals
Taylor & Francis

Appendix B: Ethical Approval

File Number: H10-11-06

Date (mm/dd/yyyy): 12/16/2011



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Rachel	Thibeault	Health Sciences / Occupational Therapy	Supervisor
Marie	Grandisson	Health Sciences / Others	Student Researcher

File Number: H10-11-06**Type of Project:** PhD Thesis**Title:** Developing Guidelines for Evaluative Research in Community-based Rehabilitation

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
12/16/2011	12/15/2012	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:

N/A

File Number: H10-11-06

Date (mm/dd/yyyy): 12/16/2011



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at: http://www.rges.uottawa.ca/ethics/application_dwn.asp

Please submit an annual status report to the Protocol Officer four weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at: http://www.rges.uottawa.ca/ethics/application_dwn.asp

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Kim Thompson

Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB

Appendix C: Consent Forms**Consent form (employees and managers).**

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University of Ottawa
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Sciences

School of Rehabilitation
Sciences

Path Out of Poverty program, Malmesbury, South Africa

I, _____, am invited to participate to the research project to evaluate the program of Goedgedacht Trust. This project is led by Marie Grandison, PhD student, Rachel Thibeault and Michèle Hébert, professors in the School of Rehabilitation Sciences, University of Ottawa.

This study aims to capture the outcomes of the program of the Path Out of Poverty (POP) program, as well as its strengths and challenges. It is part of a bigger study aimed at developing guidelines for conducting evaluations.

Participation

My participation in this project is on a period of two weeks. I will be asked to participate in _ discussion groups of approximately 2 hours each during this period. I will be asked to give my perception of how much the POP program reaches its goals, and of the obstacles and supports encountered in my experience with the organization.

Advantages and Benefits

I will not receive any financial compensation for my participation in this project. The evaluation may improve the services at *Goedgedacht Trust* and it is an opportunity to express what I think of the program.

Disadvantages and Risks

I will not be exposed to any risk since my participation consists of sharing my opinions on the POP program, and the information shared will never be associated with my name. I will not be asked to share my perception in front of people that may be in position of authority over me. At any moment, I am free to share my opinions or not and I can choose to withdraw from the project.

Confidentiality

The researchers told me that all the information shared remains confidential. The information is used in the context of this project only. No information that could identify me will be used in any report, article, or presentation following this evaluation. In addition, I confirm that I will keep the information shared by other group members confidential, meaning that I will not share their opinions with anyone, including the program managers. However, I am aware that there is a possibility that other participants share information outside the group, although they have all agreed to keep confidentiality. I also understand that the information will be free from all nominal information before being shared with the program managers. Audiorecording will be used in order to ensure that the participants' thoughts are well captured.

The findings from the discussion groups will be kept locked in the office of one of the investigators at the University of Ottawa until July 2017 when they will be destroyed (paper copy shredded, electronic copy securely deleted).

Freedom to consent and withdraw

My participation is entirely voluntary, I may decide not to participate in this study and I may decide to withdraw at any moment, without any consequence. My decision will not affect my work at *Goedgedacht* and my superiors will not be informed that I decided to join or not. The nature of the evaluation of the program at *Goedgedacht* was explained to me and the researchers have answered all my questions. At any time, I may ask additional questions concerning this study. I consent to participate in the evaluation of *Goedgedacht* program.

Resource persons

For more information on this project, I can communicate with Marie Grandisson: (phone number) or (email). I can also contact her supervisors, Professor Rachel Thibeault (phone number) or (email), Professor Michèle Hébert at (phone number) or (email). They can all be contacted by mail at: University of Ottawa, 451 Smyth, Room 3064, Ottawa (ON) Canada, K1H 8M5.

To obtain information on my rights as participant to this study, I can communicate with the responsible of research ethics at the University of Ottawa, 550 Cumberland, Tabaret Hall Room 154, Ottawa, Ontario, Canada, K1N 6N5, Tel: 001-613-562-5387 or ethics@uottawa.ca.

Note: There are two copies of this consent form. One of these is mine and the second one shall be returned to the researchers.

Participant's name: _____ Signature: _____ Date: _____

Investigator's name: _____ Signature: _____ Date: _____

Consent form (parents).**Path Out of Poverty program, Malmesbury, South Africa**

I, _____, am invited to participate to the research project to evaluate the program of *Goedgedacht Trust*. This project is led by Marie Grandison, PhD student, Rachel Thibeault and Michèle Hébert, professors in the School of Rehabilitation Sciences, University of Ottawa, Canada.

This study aims to capture the outcomes of the program of the Path Out of Poverty (POP) program, as well as its strengths and challenges. It is part of a bigger study aimed at developing guidelines for conducting evaluations.

Participation

My participation in this project consists of participating in one discussion group of 2.5 hours. I will be asked to give my perception of how much the POP program reaches its goals, and of the obstacles and supports encountered in my perception of my child's experience at *Goedgedacht*.

Advantages and Benefits

I will not receive any financial compensation for my participation in this project. I will be provided with food at the end of the group sessions. The evaluation may improve the services at *Goedgedacht Trust* and it is an opportunity to express what I think of the program.

Disadvantages and Risks

I will not be exposed to any risk since my participation consists of sharing my opinions on the POP program, and the information shared will never be associated with my name. I will not be asked to share my perception in front of people working or managing services at *Goedgedacht*. At any moment, I am free to share my opinions or not and I can choose to withdraw from the project.

Confidentiality

The researchers told me that all the information shared remains confidential. The information is used in the context of this project only. No information that could identify me will be used in any report, article, or presentation following this evaluation. In addition, I confirm that I will keep the information shared by other group members confidential, meaning that I will not share their opinions with anyone, including the program managers, employees or parents. However, I am aware that there is a possibility that other participants share information outside the group, although they have all agreed to keep confidentiality. I also understand that the information will be free from all nominal information before being shared with the program managers. Audiorecording will be used in order to ensure that the participants' thoughts are well captured.

The findings from the discussion groups will be kept locked in the office of one of the investigators at the University of Ottawa until July 2017 when they will be destroyed (paper copy shredded, electronic copy securely deleted).



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Freedom to consent and withdraw

My participation is entirely voluntary, I may decide not to participate in this study and I may decide to withdraw at any moment, without any consequence. My decision will not affect the fact that my child receives services at *Goedgedacht*. The managers and employees of the organization will not be informed whether I chose to participate or not, except for the community outreach worker an interpreter, who have signed a letter confirming he will not share this information. The nature of the evaluation of the program at Goedgedacht was explained to me and the researchers have answered all my questions. At any time, I may ask additional questions concerning this study. I consent to participate in the evaluation of Goedgedacht program.

Resource persons

For more information on this project, I can communicate with Marie Grandisson: (phone number) or (email). I can also contact her supervisors, Professor Rachel Thibeault (phone number) or (email), Professor Michèle Hébert at (phone number) or (email). They can all be contacted by mail at: University of Ottawa, 451 Smyth, Room 3064, Ottawa (ON) Canada, K1H 8M5.

To obtain information on my rights as participant to this study, I can communicate with the responsible of research ethics at the University of Ottawa, 550 Cumberland, Tabaret Hall Room 154, Ottawa, Ontario, Canada, K1N 6N5, Tel: 001-613-562-5387 or ethics@uottawa.ca.

Note: There are two copies of this consent form. One of these is mine and the second one shall be returned to the researchers.

Participant's name: _____ Signature: _____ Date: _____

Investigator's name: _____ Signature: _____ Date: _____

Verbal consent script for discussion group (parents).

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Sciences

Purpose: Before we start, we want to explain the purpose of what we are doing together today. We are evaluating the Path Out of Poverty program of *Goedgedacht* to capture what it is accomplishing and its main strengths and challenges. It is part of a bigger project to establish how evaluations should be done.

Participation: Your participation consists of participating in one discussion group of approximately 2.5 hours. You will be asked to give your perception of how much the POP program reaches its goals, and of the obstacles and supports encountered in association with your child's experience at *Goedgedacht*. Please know that your input is important to us and can contribute to shape the future of *Goedgedacht*. However, you must know that you are not obligated to participate today and can decide to change your mind at any time during or in between the sessions. Your decision to participate or not will not affect the fact that your child receives services at *Goedgedacht*.

Advantages and Benefits: You will not receive any financial compensation for your participation in this project. You will be provided with food at the end of the group sessions, whether you complete the session or decide not to participate. The evaluation may improve the services at *Goedgedacht Trust* and it is an opportunity to express what you think of the program.

Disadvantages and Risks: You will not be exposed to any risk since my participation consists of sharing your opinions on the POP program, and the information shared will never be associated with my name. You will not be asked to share your ideas in front of people working at *Goedgedacht*. At any moment, you are free to share your opinions or not and you can drop out of from the project.

Confidentiality: Please note that all the information that you share with us today will not be associated with your name, neither in the report published, or in discussions with the managers of *Goedgedacht*. Also note that we will use an audiorecorder in order to make sure that we understand well what you share with us. Since we are a group of people, we ask that everyone respect the confidentiality of other group members, meaning that information shared in the group today should not be shared with anyone outside the group. However, we need to tell you that there is a possibility that other participants share information outside the group, although they have all agreed to keep confidentiality.

Is the project clear to you? Do you have any questions for us before we start? Please raise your hand if you feel that the project was explained in enough details to you and if you agree to participate in the discussions and not to share information from the discussions to people outside the group. Note that you can ask questions at any time during the sessions, in between the sessions, or even after your participation is completed by asking us or contacting the ethics committee of the University we are affiliated with (contacts will be provided if they wish). Is it ok if we start?

Verbal consent script for observations (employees and volunteers).



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University of Ottawa
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Sciences

School of Rehabilitation
Sciences

Purpose: We are evaluating the Path Out of Poverty program of *Goedgedacht* to capture what it is accomplishing and its main strengths and challenges. It is part of a bigger project to establish how evaluations should be done.

Participation: One part of the evaluation is simply to observe what usually happens in the preschool. Today, we would like to spend the day with you in the preschool and observe the normal activities. We will not take part in the activities; we will let you do your work as you usually do. We will look at the activities done, the interactions between children, as well as between children and staff. We will not take any note that could identify you, nor any child. At the end of the day, we will ask you whether today was representative or not of your daily routine. Please know that these observations are an important component of the evaluation of the program at *Goedgedacht*, but you may decide that you don't want us to observe your group today. If so, we will not observe your group and we will concentrate on the other groups.

Advantages and Benefits: You will not receive any financial compensation. The evaluation may contribute to improving the services at *Goedgedacht*.

Disadvantages and Risks: You will not be exposed to any risk since we will observe the daily activities and we will not have anyone do something that they do not usually do.

Confidentiality: Your superiors will receive general information about this, but the information will never be associated with your name and it will be impossible for them to know in which group we observed what.

Is the project clear to you? Do you have any questions for us? Note that you can ask questions at any time today, or after today, by contacting us or the ethics committee from our University in Canada (contacts will be provided if they wish). Is it ok that we observe what is happening normally in the preschool today?

Appendix D: Discussion Group Guide

Note that the exact content of the discussion groups will be adjusted according to the first two phases of the study (systematic review and experts' consultation). The plan so far is that each discussion group will meet twice for approximately 2.5 hours.

Write the questions and record the ideas on a flipchart.

At the first meeting for each group: Explain the project, answer questions, present consent forms and sign them.

Meeting A (managers only)

Validating the logical model for EDC. Conduct the logical analysis by completing the logical model together (we started one with the information from last year, need to validate it). Post-it on walls of context, needs, objectives, activities, resources.

Meeting B (one group with managers, one group with staff-volunteers-leader)

1) Start documenting the **implementation** of the ECD (ideal and actual), the process analysis. Daily activity log: a) collective constructions on ideal routine at first, then on normal routine (what actually happens), b) time to clarify things on their own sheet (2 sided with ideal day structure on one side, and normal day on the other), anonymously. (include words in description of ECD on website: This unit provides a safe and happy space for small children at this very critical time in their lives. The days are filled with stimulating activities, good food, games, rest and lots of cuddles.)

2) Continue documenting the **implementation**: ask if they have any data on the number of children present per day (and information on them), number of staff and volunteers, training received. If so, plan a small meeting with a representative to look at it.

3) **Select outcome measures** in preparation for outcome analysis: If you wanted to tell the story of what happens when children join the EDC program, how would the story end, what changes could be observed at the end or along the way. a) We will provide them with a list of potential outcome measures inspired by data gathered last year at *Goedgedacht*, the CBR Guidelines, as well as readings for early development center for children with FASD or living in poverty (this list will be in a paper format in front of them (one outcome measure per sheet), and on flip chart). b) We will ask them for other ideas of outcome measures that we haven't thought of, to add to the list. c) We will then eliminate from the list the outcome measures that are considered of low importance of relevance to people. d) We will then do a rating activity in terms of importance for them for the 5 outcome measures that they consider important (p.41 & 45 SAS, keep track of the reasons, discuss the rank until everyone agrees (consensus or majority vote: rating scale on the floor on which people place the different ideas, one side in Afrikaans, other side in English). e) We will also ask for their ideas on potential indicators for the 5 most important outcome measures (and complement it with literature, and brainstorming session 2nd week, 5 points are given to a measure ranked 1, 4 to a measure ranked 2, etc.). f) Explain to them that the same exercise will be done with the task team and managers, and that we will talk to some parents as well, in order to know their opinion on the most important outcome measures.

4) Invite participants to come share any additional thought to us or to put it in the box at the exit (to allow further disclosure if necessary).

Meeting C: (one group with managers, one group with staff-volunteers-leader, one group with parents)

- 1) Evaluate perceptions of POP-ECD performance (outcome analysis) on the 3 outcome measures chosen (three most popular in three groups). Can be done through progressive functional indicators using socratic wheels to measure, and ask them reasons for each score (group consensus needed, record reasons).
- 2) Evaluate perceived facilitators and challenges (process analysis), as well as potential solutions. We present them the facilitators and challenges discussed last year, ask them if there are any others, and then come to a consensus on 3 most important facilitators and 3 most important challenges along with reasons for their choice (sabotage, ideal scenario or not). These will be put on the wall in front of the wheel, to illustrate either obstacles (bombs or big rocks in the road) or facilitators (flat road or someone pushing the wheel)
- 3) Discuss potential solutions as a group (what would make your life-work easier, what could help flatten the road or push the wheel to go faster).
- 4) Present them the 4 boxes to evaluate the evaluation (see description below).

Feedback on the process _____

We would love to know your satisfaction, what you like, what you didn't like so much, and suggestions for improvements in the evaluation process. The idea is that we want to make improvements as well.

We would really appreciate both positive and negative comments. You may sign your name if you want us to know that you wrote that, but you don't have to. It is written on each box what type of comments of may give us and each box is of a different color.

You have until Thursday night to complete it, we will have it with us when meeting with groups, and it will be in the POP office the remaining of the time. Tell them that they are also very welcomed to share comments verbally!

Appendix E: Round 1 Invitation Email to Experts

Your opinion matters:

What are best practices in CBR program evaluation

Dear CBR expert,

Because of your experience in community-based rehabilitation (CBR), you have been selected to participate in an experts consultation about CBR program evaluation. The publication of the CBR Guidelines in 2010 (WHO, ILO, UNESCO, & IDDC) certainly facilitates the implementation of CBR programs around the world. Nevertheless, although the need for program evaluation is stressed, insufficient directions are provided to help stakeholders combine best practices in program evaluation, the reality of resource-poor areas, and the core CBR values of participation and empowerment.

In order to fill this gap, our research project (Marie's PhD thesis) is aimed at providing guidelines on how program evaluations should be conducted in CBR. Prior to this consultation, a systematic review of articles for CBR program evaluation, a field study in South Africa, and a review of textbooks on best practices in program evaluation were conducted ([click here to see a summary of key findings from these previous phases](#)).

The goal of this consultation is to build consensus on best practices in CBR program evaluation, including the process to follow, criteria for choosing appropriate data collection methods, and frameworks that could be used to situate program evaluations. The results will be sent to the World Health Organization (WHO), as they are currently developing a manual for CBR program evaluation in collaboration with organizations all around the world. Your participation in this consultation can therefore be beneficial to you, your partners and the CBR community in general.

We estimate that approximately 45 minutes of your time will be required to answer our questionnaire. You may choose to complete it at different times using the *Save and continue later* option at the bottom of each page. You can access the questionnaire by clicking on the link below:

http://fluidsurveys.com/s/CBR_programevaluation/

In order to generate consensus, **there are two rounds in this consultation.** We will therefore contact you one more time in 2014 with: 1) a summary of the results from this first round and, 2) an invitation to complete a second questionnaire. This is why we will ask for your name and email address when you complete the questionnaire.

To acknowledge your contribution, we will be glad to add your name to the collaborators of the manuscript that will be published following this consultation.

Sincere thanks for your generosity,

Marie Grandisson, PhD (Cand.), Rachel Thibeault, PhD & Michèle Hébert, PhD
School of Rehabilitation Sciences, University of Ottawa, Canada



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Sciences

School of Rehabilitation
Sciences

For more information or for a *Microsoft Word* version of the questionnaire:

Please contact Marie Grandisson at (email).

You should also receive a paper copy by mail soon.

Project approved by the Office of Research Ethics, University of Ottawa (H10-11-06)
Support from Vanier Graduate Scholarship (CIHR), University of Ottawa & COTF

Reminder: Definitions of community-based rehabilitation and program evaluation

What is community-based rehabilitation?

Community-based rehabilitation (CBR) is defined as *a strategy within general community development for the rehabilitation, equalization of opportunities, poverty reduction, and social inclusion of people with disabilities*¹. CBR programs are present in more than 90 countries², mostly in resource-poor areas, in order to foster community development that is as inclusive as possible of people with disabilities and their families. These programs are usually implemented through the combined efforts of people with disabilities, their families, community workers, health professionals, and communities. It includes work to promote social inclusion, empowerment, as well as access to education, to decent work opportunities, and to preventive, rehabilitative, and curative health services.

What is program evaluation?

Program evaluation means assessment.² It is about capturing what a program is doing to meet the needs of a community and whether it is having the intended impact in the best possible way. In other words, program evaluation is about judging the worth of an intervention through systematic investigation using methods that are scientifically valid and socially relevant.³

1: ILO, UNESCO, & WHO. (2004). *CBR: A strategy from rehabilitation, equalization of opportunities, poverty reduction, and social inclusion of people with disabilities (joint position paper)*. Geneva, CH: WHO Press. Retrieved 2011/02/11 from:
http://whqlibdoc.who.int/publications/2004/9241592389_eng.pdf

2: WHO, UNESCO, ILO, & IDDC. (2010). *Community-Based Rehabilitation: CBR Guidelines*. Malta: WHO Press. Retrieved 2012/09/04 from:
<http://www.who.int/disabilities/cbr/guidelines/en/index.html>

3: Brousselle, A., Champagne, F., Contandriopoulos A.-P. & Hartz, Z. (Eds) (2009). *L'évaluation: concepts et méthodes*. Montréal, QC: Les Presses de l'Université de Montréal.

Appendix F: Round 1 Questionnaire for Experts

Community-Based Rehabilitation Program Evaluation
Building consensus on what should be considered best practices

Instructions:

Please read the questions and share your opinion. Your answers and suggestions are extremely important for this project, which is part of a PhD thesis at the University of Ottawa. The goal of this consultation is to build consensus around what should be considered best practices in community-based rehabilitation (CBR) program evaluation.

This questionnaire has 4 sections. The first one contains sociodemographic information. In the second and third sections, you will be asked for your opinion on the characteristics of the program evaluation process and on the most suitable data collection methods for CBR. In the last section, you will be invited to comment on potential frameworks that could be used for CBR program evaluation.

Contact information:

Please enter your name and email address below. Your answers will not be associated with your name in the analysis of the questionnaire.

Name: _____

Address: _____

SECTION 1: SOCIODEMOGRAPHIC INFORMATION
1. How many years of experience in CBR do you have?

Please include both direct experience in the field and indirect experience (e.g. teaching, research).

- ☐ None
- ☐ Less than 5 years
- ☐ 5-9 years
- ☐ 10-19 years
- ☐ 20 years or more

2. Where have you been involved in CBR programs?

Please select all that apply.

- ☐ Asia
- ☐ Africa
- ☐ Europe
- ☐ North America
- ☐ South America
- ☐ Australia
- ☐ I have never been directly involved with CBR programs.

If you answered 'None' to question #1 OR 'I have never been directly involved with CBR programs.' to question #2, you can stop here.

The other questions concern people working in CBR.

3. Which of the following categories best represents you?

- ☐ Researcher
- ☐ Graduate student
- ☐ Employee of a United Nations organization involved in CBR (e.g.: WHO)
- ☐ Employee of a non-governmental organization (NGO) involved in CBR (e.g. Handicap International)
- ☐ Funder of CBR programs
- ☐ Regional, provincial, or national coordinator for CBR
- ☐ Manager of a local CBR program
- ☐ Community worker
- ☐ Other, please specify: _____

4. In a typical year, how much time do you spend in the field with local CBR programs?

- ☐ None
- ☐ Less than 1 month
- ☐ 1-4 months
- ☐ 5-8 months
- ☐ 9-12 months

5. In which country do you live?

Please answer according to where you are considered a resident or a citizen, not where you may live temporarily for the duration of a contract.

6. Please note that the following question is asked to make sure that the voices of people with disabilities are being heard during this consultation.**Do you have a physical, intellectual, sensory or psychosocial disability?**

- ☐ Yes
- ☐ No
- ☐ I prefer not to share this information.

7. Have you ever been involved in the evaluation of a CBR program?

- ☐ Yes
- ☐ No
- ☐ I don't know.

8. How many years of experience in program evaluation do you have?

Please include experience evaluating all types of programs, not only CBR.

- ☐ None
- ☐ Less than 5 years
- ☐ 5-9 years
- ☐ 10-19 years
- ☐ 20 years or more

SECTION 2: CBR PROGRAM EVALUATION PROCESS

9. a) In your opinion, given your experience and the context in which you work, what would be the main reasons to carry out CBR program evaluations?

Rank the following reasons from 1 to 5, 1 being the most important.

- ☐ Show donors that the program works
- ☐ Show beneficiaries and families that the program works
- ☐ Obtain information to facilitate decision-making about a particular program, including whether it works or not and how to improve it
- ☐ Prove that CBR is effective on the global scene (i.e. build the evidence base)
- ☐ Understand the conditions conducive to the effectiveness of CBR in order to replicate good programs

b) Please share any comments on your ranking.

c) Are there any other reasons to carry out CBR program evaluations that you deem important? If so, which one(s)?

10. From our review of the literature and our field study, we have identified 7 important criteria for CBR program evaluation processes. These are:

1. Being flexible (making adjustments as needed)
2. Being inclusive (engaging all key stakeholders in the evaluation)
3. Being empowering (giving control to the community while building local capacity)
4. Being free of miscommunication (being clear about project management & transparent in the sharing of findings)
5. Being sustainable (designing a responsive evaluation, which will not drain too many resources and will eventually be embedded in the organization)
6. Generating well-founded and accurate conclusions (achieving the most precise findings possible using different strategies)
7. Being focused on action (making sure that concrete steps will follow evaluation)

a) From your perspective, which criteria for CBR program evaluation processes are the 3 most important?

- ☐ Being flexible
- ☐ Being inclusive
- ☐ Being empowering
- ☐ Being free of miscommunication
- ☐ Being sustainable
- ☐ Generating well-founded and accurate conclusions
- ☐ Being focused on action

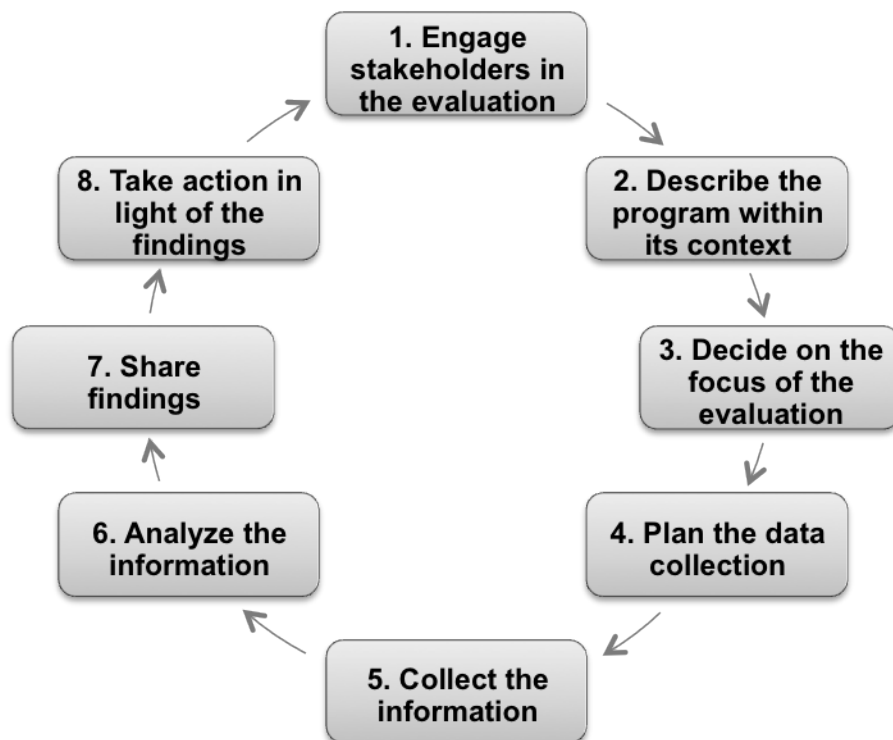
b) Please tell us why the criteria you selected in “10a)” are the most important.

c) From your perspective, are any of these criteria not essential? If so, which one(s) and why?

d) Are there any other criteria for CBR program evaluation processes that you deem very important? If so, which one(s) and why?

11. From our review of the literature and our field study, we have identified 8 steps for CBR program evaluations.

Figure 1: Steps to follow when carrying out a CBR program evaluation



a) From your perspective, are any of these steps not essential? If so, which one(s) and why?

b) Would you add any other steps? If so, which one(s) and why?

c) From your perspective, which step(s) need to be emphasized? Why?

**d) Would you modify any of these steps or the order in which these are presented?
If so, please explain.**

SECTION 3: DATA COLLECTION METHODS FOR CBR PROGRAM EVALUATION

12. a) Which data collection methods would you most likely use if you conducted a CBR program evaluation?

Rank the first 5 methods you think you would use considering your knowledge, resources, preferences, and the context in which you would use them, 1 being the most likely.

- ☐ Discussion groups (or focus groups)
- ☐ Individual interviews
- ☐ Written surveys or questionnaires
- ☐ Observations (in the program or through a community visit)
- ☐ Individual assessments (to measure the difference between initial and current levels of well-being, health, or performance in activities)
- ☐ Review of statistics (e.g. national or World Bank databases)
- ☐ Review of documents (e.g. annual report or the organization, national guidelines, etc.)
- ☐ Photovoice

b) Please share your reasons for your preferences.

c) Are there any other methods that you would be likely to use? If so, which one(s) and why?

d) How would you ensure a suitable fit between local communities and the evaluation methods you suggest?

13 a) Concerning the selection of indicators during program evaluation, which of these options do you believe is most suitable for CBR?

An indicator is a variable that can be measured over time to reveal meaningful change (CDC, 1999; WHO, 2011), it is what we measure. E.g. proportion of children with disabilities who go to school, proportion of adults with disabilities who are employed.

- ☐ Using universal indicators (which can be used across the world in different CBR programs and could come from a bank of ready-to-use indicators)
- ☐ Using context-specific indicators (which can be generated with the local community)
- ☐ Using a combination of universal and context-specific indicators
- ☐ I don't know.

b) Please share your reasons.

14. a) Do you believe that CBR data collection methods should be:

- ☐ Qualitative? (e.g. interviews, discussion groups, etc.)
- ☐ Quantitative? (e.g. scales and individual assessments)
- ☐ Mixed? (a combination of qualitative and quantitative)
- ☐ Qualitative, quantitative or mixed? (depending on the situation)
- ☐ I don't know.

b) Please share your reasons.

15. There is disagreement between CBR authors concerning the need to use tools (e.g. checklists, questionnaires, scales) that are context-specific versus universal. Tools are what we use to measure program process or outcomes, how we measure.

a) What is your position on this topic?

- ☐ Context-specific tools should be used as much as possible (e.g. Quality of Life scale developed for that specific community).
- ☐ Universal tools should be used as much as possible (e.g. Quality of Life scale which has been validated through research).
- ☐ Both can be relevant, depending on the situation.
- ☐ I don't know.

b) Please share your reasons.

16. In our experience, using interactive tools and strategies fosters active engagement of people of all educational levels in evaluation activities.

Such tools and strategies are exercises or techniques that promote active participation through the use of more visual representations and less verbal requirements: people are asked to list, sort, or organize their thoughts on a topic in a climate of equality and openness. Exercises may be done on a wall, on the floor or on a table, depending on the resources, the people, and the objective of the activity (Chevalier & Buckles, 2008).

a) Have you ever used interactive tools and strategies?

- ☐ Yes
- ☐ No
- ☐ I am not sure.

b) Please share your comments on the use of interactive tools and strategies.

You may include groups or situations for which you think their use is more relevant.

17. What are your strategies when carrying out evaluation activities with people speaking different languages?

18. During our field study, we found it challenging to collect objective information to measure changes in the beneficiaries, the families or the community since the implementation of the program. One of the reasons is that we did not find simple, accessible, and rigorous tools that could eventually be used by program staff.

Do you know of any simple, accessible and rigorous tool(s) to collect objective information for CBR program evaluation?

- ☐ Yes. Which one(s)?

 - ☐ No
 - ☐ I am not sure. Please explain.

-

SECTION 4: FRAMEWORK FOR CBR PROGRAM EVALUATION

In the context of program evaluation, a framework is a “*practical, non prescriptive tool, designed to summarize and organize the essential elements of program evaluation*” (CDC, 1999, p.4). It is often used interchangeably with the word ‘model’. Many different frameworks have been used in CBR and this makes it difficult to combine findings from different evaluations. As a consequence, it is hard to say under which conditions CBR works best. Using a shared framework to situate findings could help in building a more solid evidence base for the effectiveness of CBR.

In the CBR literature, some authors argue that a shared framework is needed while others believe that frameworks should always be context-specific.

19. a) Do you believe CBR needs a shared framework for program evaluation in which to situate findings of studies and evaluations?

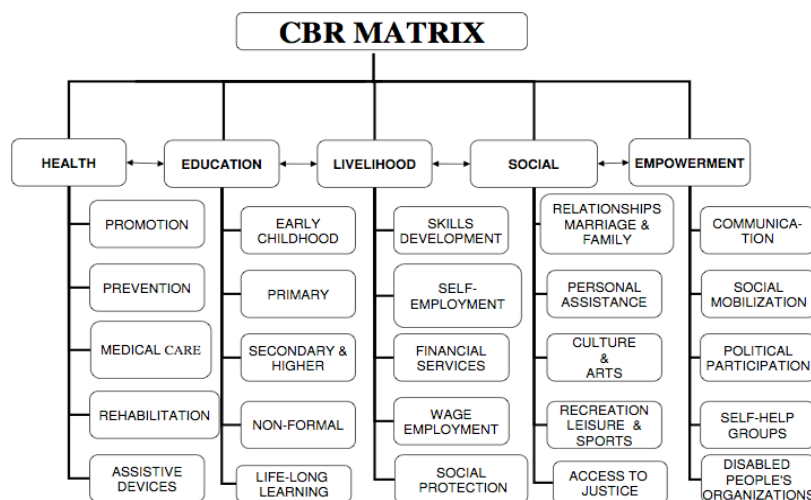
- ☐ Yes
☐ No
☐ I don't know.

b) Please share your reasons.

One possibility is that the CBR Matrix proposed by ILO, UNESCO and WHO (2004) could provide the basis for a shared framework.

The CBR Matrix 5 main components match the 5 key development sectors targeted by CBR programs (i.e. health, education, livelihood, social, empowerment), while the 25 elements correspond to areas for development within each sector. A CBR program could easily situate its evaluation within the matrix (e.g. in the livelihood component, more specifically in the self-employment element, to verify whether it has contributed to poverty reduction). The matrix is congruent with inclusive community development and was built from exhaustive experts consultation and field validation.

Figure 2: The CBR Matrix (ILO, UNESCO, & WHO, 2004)



20. a) To what extent do you agree or disagree that a shared framework for CBR program evaluations should be based on the CBR matrix?

- ☐ Strongly Agree
- ☐ Agree
- ☐ Undecided
- ☐ Disagree
- ☐ Strongly Disagree

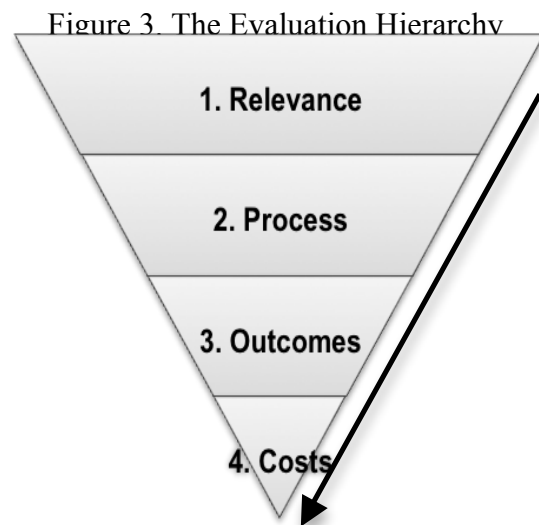
b) Please share your reasons, comments and suggestions.

Another possibility is that CBR program evaluations could follow the Evaluation Hierarchy proposed by Rossi, Lipsey and Freeman (2004).

Consequently, evaluations could:

- first look at **relevance** (whether program activities fit community needs and address service delivery gaps);
- then examine **process** (how the program is implemented, its resources, its major strengths and weaknesses);
- then look at program **outcomes** (desirable and unintended);
- and finally analyze program **costs** (cost-benefit and cost-effectiveness).

This does not mean that evaluations should always include all four elements. Rather, this suggests that conclusions about program outcomes should rest on analyses of how it was implemented and of its congruence with community needs.



21. a) To what extent do you agree or disagree that CBR program evaluations should start with analyses of relevance, and then move on to process, outcomes and costs analyses?

- ☐ Strongly Agree
- ☐ Agree
- ☐ Undecided
- ☐ Disagree
- ☐ Strongly Disagree

b) Please share your reasons, comments and suggestions.

We would like to suggest combining the CBR matrix and the Evaluation Hierarchy into a CBR program evaluation framework.

The framework below could become our shared CBR program evaluation framework: it could act as a menu from which to select priorities for evaluation, provide structure to the evaluation process, and guide the choice of process and outcome measures. CBR evaluations could fill in the boxes that are relevant for the program assessed, i.e. to document the evaluation process using this table. A real-life application can be found in Figure 5.

Figure 4. Proposed CBR program evaluation framework

		Evaluation Hierarchy			
		Relevance	Process	Outcomes	Cost
CBR Matrix	Health - Promotion - Prevention - Medical care - Rehabilitation - Assistive devices				
	Education - Early childhood - Primary - Secondary & higher - Non-formal - Lifelong learning				
	Livelihood - Skills development - Self-employment - Wage employment - Financial services - Social protection				
	Social - Personal assistance - Relationships, marriage & family - Culture & arts - Recreation, leisure & sports - Justice				
	Empowerment - Advocacy & communication - Community mobilization - Political participation - Self-help groups - Disabled People's Organizations				

Figure 5: An application of the CBR program evaluation framework

		Evaluation Hierarchy			
		Relevance	Process	Outcomes	Cost
CBR Matrix	Education - Early childhood - Primary - Secondary & higher - Non-formal - Lifelong learning	<u>Needs:</u> Developmental delays are very present because of poor nutrition, poor stimulation and fetal alcohol spectrum disorders. No low-cost and accessible option was available in the area. <u>Activities:</u> The program includes a low-cost early childhood centre for vulnerable children where they are fed and stimulated.	<u>Major facilitators:</u> Staff is dedicated, material resources are adequate (games, building). <u>Major obstacles:</u> Insufficient training is available for staff on children's development and FASD. Transportation of the children to the center drains a large proportion of the financial resources.	<u>Readiness for school:</u> Parents, staff & managers believe children are a little bit more ready for school after attending the early childhood development centre, School readiness assessment shows small but significant positive difference. <u>Motor development:</u> Staff believes children reach development milestones, but parents and managers don't. Motor development checklist shows that most don't.	Analyses suggest that it costs 200\$ per year to get one more child school ready.

22. a) Do you believe that the framework proposed above could become our shared CBR program evaluation framework?

- ☐ Yes, definitely!
- ☐ Yes, with modifications.
- ☐ No
- ☐ I don't know.

b) Please tell us your suggestions to improve the proposed CBR program evaluation framework. You do not need to include suggestions in all the boxes.

What you would ADD	
What you would REMOVE	
What you would MODIFY	

MANY THANKS FOR YOUR GENEROSITY!

*Thank you for having taken the time to participate in this study and
for your contribution to the advancement of CBR program evaluation!*

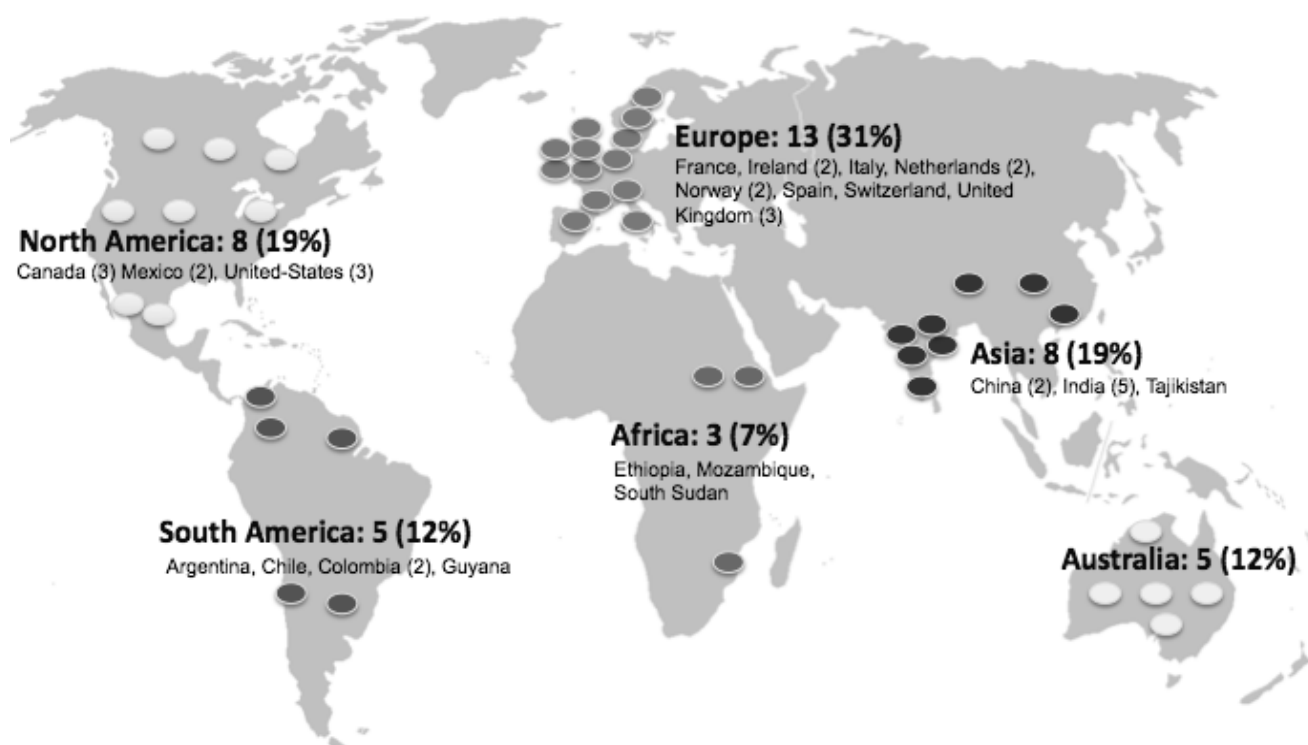
Appendix G: Summary of Round 1 Findings

Findings from Round 1: CBR Program Evaluations

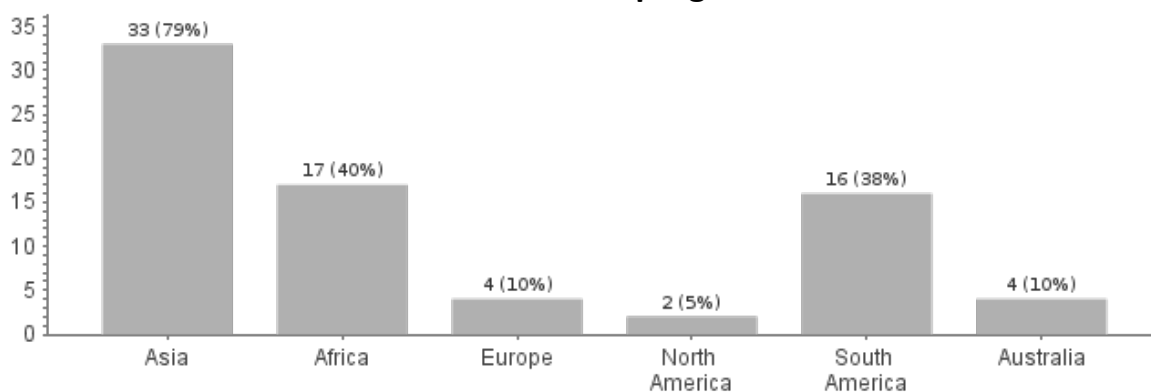
You are 1 of 42 individuals who completed the questionnaire:

- All have experience in CBR.
- 88% have been involved in a CBR program evaluation.
- 12 are NGO employees, 12 are researchers, 5 are coordinators, 2 are employees of United Nations organizations, 3 are consultants, 2 are involved in university-based centers, 2 are funders and consultants, 1 is a program manager, 1 is a community worker, 1 is a funder, and 1 has worked for United Nations organizations and NGOs.
- 5 have a disability.

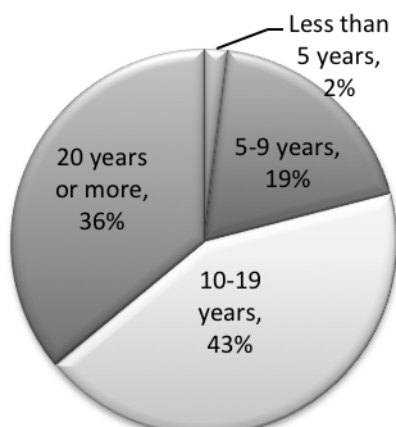
You live all around the world!



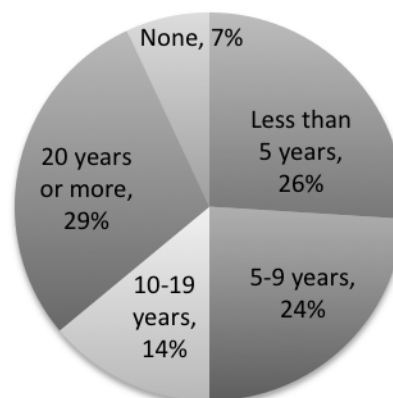
You have been involved in CBR programs on all continents!



You are highly experienced in CBR !



You have experience in program evaluation as well !



Have we reached consensus?

Yes, on many issues! These are summarized in the table below. Consensus is reached when 75% or more agree with a proposition. The % in brackets refers to the percentage of the 42 panellists who agreed in Round 1.

Consensus reached: Best practices for CBR program evaluations			
Mixed methods should be used (79%) ¹ .	Context-specific AND universal indicators should be combined (90%).	Both context-specific and universal data collection tools can be relevant (81%).	A shared framework is desirable (81%) ² .

1: 21% believed that quantitative or qualitative methods alone could also be appropriate depending on the evaluation question, the resources available and the context.

2: 17% were undecided and only 2% disagreed that a shared framework was desirable.

What are key ingredients of good CBR evaluations?

You had to select the 3 most important criteria out of a list of 7. Being inclusive (83%) and being empowering (69%) were valued most.

Your comments also highlighted:

- The need to combine data collection methods in order to enable triangulation.
- The usefulness of participatory tools to facilitate participation of all in evaluation activities and their congruence with CBR principles of inclusion and participation. 86% had used them and you suggested that they could facilitate participation during interviews or discussion groups.
- The importance of paying attention to the impact of cultural differences.

- The steps that should be emphasized in all evaluations: engaging stakeholders during the whole process, sharing findings with appropriate audiences, and taking action in light of the findings.
- The importance of a monitoring system and baseline data.
- Useful strategies when evaluators and local stakeholders speak different languages.

The debate continues as to the content of the shared framework.

- 71% thought it should be based on the CBR Matrix. If we exclude those who were undecided from the analyses, 83% of the panel thought so.
 - The main arguments in favor are: it represents CBR today as an inclusive community-development strategy, and it is widely known and accepted.
 - The main arguments against are: CBR principles are not well represented, it is too vague, and people outside the disability sector don't know it.
- Only 51% believed that it should follow the evaluation hierarchy, starting with relevance, and moving to process, outcomes and costs analyses.
- Your comments also highlighted that:
 - It needs to be simple and flexible.
 - 4 of you suggested CBR principles are more important than the CBR Matrix.
 - You provided many ideas of elements that could be evaluated that may or not fit in a shared framework.

Here are the names of our generous panellists:

- | | | | |
|---------------------|---------------------------------|----------------------|---------------------|
| ▪ Binoy Acharya | ▪ Priscille Geiser | ▪ Jay Kumar | ▪ Lieve Sabbe |
| ▪ Marieke Boersma | ▪ Ann Goerdts | ▪ Gwynnyth Llewellyn | ▪ Pedro Safrao |
| ▪ Svein Brodtkorb | ▪ Cindy Greer | ▪ Sue Lukersmith | ▪ Rachel Tainsh |
| ▪ Yinghong Cai | ▪ Geraldine Halls | ▪ Malcolm MacLachlan | ▪ Maya Thomas |
| ▪ Eva Yin-han Chung | ▪ Gulliver Ishmael | ▪ Ros Madden | ▪ Sara Varughese |
| ▪ Huib Cornielje | ▪ Djenana Jalovcic | ▪ Hasheem Mannan | ▪ Wim van Brakel |
| ▪ Israel Cruz | ▪ Sally Hartley | ▪ Stephen Muldoon | ▪ Andrea Vogt |
| ▪ Sunil Deepak | ▪ Jorge Herminio Morales Nájera | ▪ Malcolm Peat | ▪ Angela Wangda |
| ▪ Eduardo García | ▪ Chapal Khasnabis | ▪ Eladio Recabarren | ▪ David Werner |
| ▪ Solangel Garcia | ▪ Pim Kuipers | | ▪ Mary Wickenden |
| ▪ Brigitte Gautron | ▪ Jayanth Kumar | | ▪ Victoria Zubiarre |

Thank you for being part of this group, we hope that you will join us in Round 2!

Appendix H: Round 2 Invitation Email to Experts

June 2nd 2014

uOttawa

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences de
la réadaptation

University of Ottawa
Faculty of Health
Sciences

School of Rehabilitation
Sciences

Dear _____,

You are part of a group of experts who completed the first of 2 rounds of consultation on CBR program evaluations. Our goal is to generate consensus on what should be considered good practices in this field. **This last round focuses on validating recommendations for good CBR program evaluations based on the consensus reached in Round 1 and the substantial comments you provided.** Your input is extremely important to ensure that the guidelines emerging from this study reflect the opinions of individuals involved in CBR in different roles and regions. Your contribution will be acknowledged in all publications and presentations following this project.

We estimate that you will need 30-45 minutes to complete the questionnaire and are extremely grateful for your time. You may complete either the hard copy of the questionnaire and send it back to us in the envelope provided, or the online version using this link: http://app.fluidsurveys.com/s/CBRProgramEvaluation_Round2/.

Sincere thanks for your generous contribution and all the best in your projects.

Marie Grandisson¹, PhD (Cand.), Rachel Thibeault¹, PhD, Michèle Hébert¹, PhD, & Debra Cameron², PhD

1: School of Rehabilitation Sciences, University of Ottawa, Canada

2: Department of Occupational Science and Occupation Therapy, University of Toronto, Canada

Project approved by the Office of Research Ethics, University of Ottawa (H10-11-06)

Supported by: Vanier Graduate Scholarship (CIHR),
Michael-Smith Foreign Study Supplement (CIHR), University of Ottawa & COTF

Appendix I: Round 2 Questionnaire for Experts**CBR Program Evaluations: Building Consensus (Round 2)****Instructions**

This is the last of two rounds of a Delphi Study. Our aim is to generate practice guidelines for CBR program evaluations based on experts consensus. In this study, we consider that a consensus is reached when 75% or more agree with a proposition (% chosen according to Delphi studies literature). The guidelines will essentially be recommendations regarding the critical features of good CBR evaluations. They are intended to provide guidance to those involved in CBR evaluations as to what is generally considered good practice.

- On this first page, you may provide comments on the summary of Round 1 findings if you wish.
- Then, we will ask your opinion with regard to recommendations for practice in CBR program evaluations based on the results from the first round. The first section is aimed at validating recommendations for which consensus was reached in Round 1. In the second and third sections, other propositions based on your answers and comments from Round 1 are suggested.

Please write your name in full here.

Your answers will not be associated with your name, we simply wish to know who completed the questionnaire.

Please provide comments on the summary of Round 1.

For example : panel composition, whether your perspective is well represented.

Recommendations 1 to 5: Based on consensus reached in Round 1

Should we modify anything in the recommendations below?

If so, please provide suggestions.

Focus on what is written in bold letters. Only when needed, have a look at the bullet points for further details. Those were developed using your comments from Round 1.

Recommendations	Modifications needed?
1. Mixed methods should be used when evaluating CBR programs. (Based on 79% agreement in Round 1) - Mixed methods generally enable evaluators to draw the most comprehensive picture. - The qualitative component is more likely to facilitate participation and imbue meaning to the process. - The quantitative component will help respond to donors by providing data on the numbers affected by a program and magnitude of changes following participation. - In certain rare situations, qualitative or quantitative methods alone might be better suited.	
2. Context-specific <u>OR</u> universal data collection tools can be used when evaluating CBR programs, as long as efforts are made to ensure that they are appropriate to the culture and program. (Based on 81% agreement in Round 1) - Tools are what we use to collect information. - Both can be relevant, and may be used on their own or together. The choice of tools will depend on their availability, the intended use of the results and personal preference. - Some may prefer to use tools developed for the specific context in which they are working (e.g. Quality of Life scale developed for and with the local community). - Others may prefer to use universal tools in order to make comparisons, lobby at the international level, and take advantage of what is already available (e.g. Quality of Life scale validated through research).	

3. As much as possible, one should combine universal <u>AND</u> context-specific indicators when evaluating CBR programs. (Based on 90% agreement in Round 1) • Indicators are what we measure, they are variables believed to reveal meaningful change. • Universal indicators coming from a bank of ready-to-use CBR indicators could help to lobby for CBR on the international stage. They could be useful for measuring change on desirable outcomes that are common between many CBR programs (e.g. number of children with disabilities enrolled in primary school). Care must be taken to ensure that they are appropriate for the local reality. Alone, they are unlikely to yield the full picture of the program evaluated. • Context-specific indicators are essential to capture the specificities associated with a program and the context in which it is implemented (e.g. % of farmers who employ disabled workers). Often, they can better identify unanticipated program outcomes and impacts. These indicators can be developed with local stakeholders.	
4. The voices of all relevant stakeholders should be included in CBR program evaluations. (Based on 83% strongly believing evaluations should be inclusive in Round 1) • This includes people from different age groups with different disabilities, gender, race and religion and playing different roles such as beneficiaries, families, staff, partners, governments, donors and other community members. Those least often heard or most marginalized should be given an opportunity to express their opinions. • Conditions for their participation to be possible need to be present. Resources available will need to be taken into consideration and innovation may be needed to give a voice to most disempowered groups.	
5. CBR program evaluations should be situated within a shared framework. (Based on 81% agreement in Round 1) • A framework is a model to guide one's thinking when designing a program evaluation. • One of the main advantages of having a common framework among all people involved in CBR program evaluations would be to situate evaluation findings within this framework. This could: 1) enable the CBR community to join forces in building the evidence base regarding the effectiveness of this strategy, 2) facilitate communication and advocacy, and 3) facilitate useful comparisons across the more universal features of CBR programs. A shared framework could also provide a common understanding of what CBR aims to achieve and how.	

Recommendations 6 to 13: Based on your comments in Round 1**Do you agree with the recommendations below?****Should we modify anything?**

Focus on what is written in bold letters. Only when needed, have a look at the bullet points for further details. Recommendations 6 to 13 and their associated bullet points were developed from your answers in Round 1. We do not have consensus on those yet: we did not ask you whether you agreed or not with these propositions in Round 1. Please refer to the summary of Round 1 findings if needed.

	Do you agree?	Modifications needed?
6. The evaluation process should be designed in a way that will empower the local community, including people with disabilities. - This can include formal and informal capacity building activities such as workshops or sharing tools. Community members, including people with disabilities, may be trained to collect data. - This can also be done through a participatory evaluation process in which local stakeholders are involved and make decisions as regularly as possible.	☐ Yes ☐ No	
7. Evaluators should pay attention to the impact of cultural differences during a CBR evaluation and adapt as needed. - This includes taking time to become familiar with the local culture and its power structure, to explore how disability, health, education, and work are viewed, and to determine if all can exercise their freedom of speech. - This also includes agreeing on a shared taxonomy, especially about disability. This also means designing the process and choosing tools in collaboration with local stakeholders.	☐ Yes ☐ No	
8. Evaluators should consider using participatory tools during CBR program evaluations. These interactive tools generally rely on visuals rather than language and can facilitate the participation of all, while being especially helpful for children, as well as people with communication disabilities, with minimal formal schooling, or who are marginalized.	☐ Yes ☐ No	

9. Evaluators should encourage and support monitoring of CBR programs. Monitoring is the regular collection of information about the program over time. It can help establishing baseline and track progress, and can therefore greatly facilitate evaluations. When monitoring information is not available, retrospective baseline from key stakeholders or key documents review may be needed.	☐ Yes ☐ No	
10. Evaluators should work closely with local stakeholders throughout the CBR evaluation process. For example, local stakeholders (including people with disabilities) can be involved in defining the evaluation questions, planning the data collection, collecting the information, validating the interpretations, sharing findings, and deciding on the actions to be taken.	☐ Yes ☐ No	
11. As appropriate, findings should be shared locally and with other audiences to advance knowledge and contribute to CBR advocacy. Written reports, community meetings, leaflets, presentations at conferences, and publications in peer-reviewed journals are possible options.	☐ Yes ☐ No	
12. CBR program evaluations should always translate into action. - Action is defined broadly and could include: modifying program features, offering staff training on newly-raised issues, writing grant proposals rooted in evaluation results, or celebrating the efforts of everyone involved in the program. - This does not entail that evaluators are necessarily responsible for the actions that need to be taken in light of the findings.	☐ Yes ☐ No	
13. Strategies should be used to alleviate the impact of linguistic differences. - This is important to facilitate participation of all and ensure that evaluation results are valid. - These may include: 1) using translators belonging to the local culture and who are as neutral as possible, 2) training local native speakers to collect data, 3) learning the local language, 4) using visual tools or communication aids, 5) triangulating the data collected with field observations, and 6) being attentive to nonverbal cues.	☐ Yes ☐ No	

Can we agree on a shared framework?

In Round 1:

- The group agreed that a shared framework for CBR program evaluation was needed, but did not reach consensus on its content.
- You stressed the importance for this framework to be simple and flexible.
- 30 panellists (71%) thought it should be based on the CBR Matrix (15% undecided, 15% disagreed).
- 4 (10%) suggested that it could be associated with the CBR principles.

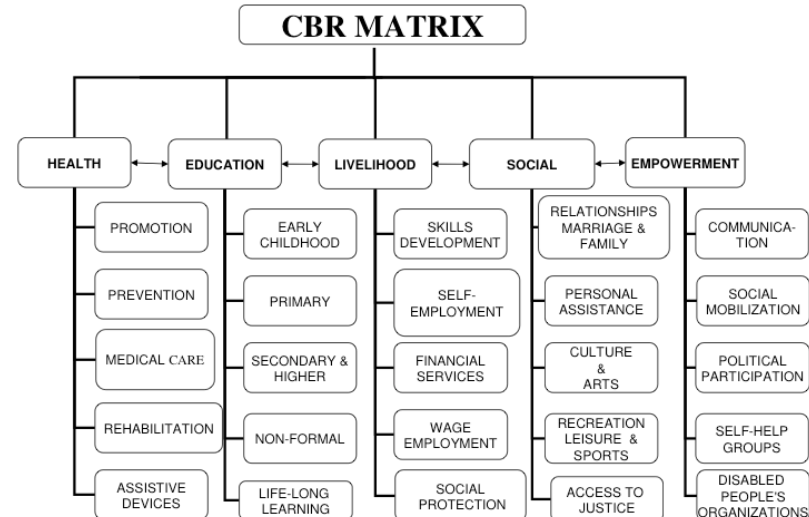
We propose to:

- Agree on a simple framework in which to situate the findings of CBR evaluations;
- Complement it with a list of other items that could be evaluated (e.g. quality of life, external support, strengths and weaknesses);
- Use the framework in a flexible way by inviting programs to select those items important to them and stressing that the framework can be adapted to local needs and realities.

Please look at the following 3 suggestions based on your responses in Round 1 and tell us what you think.

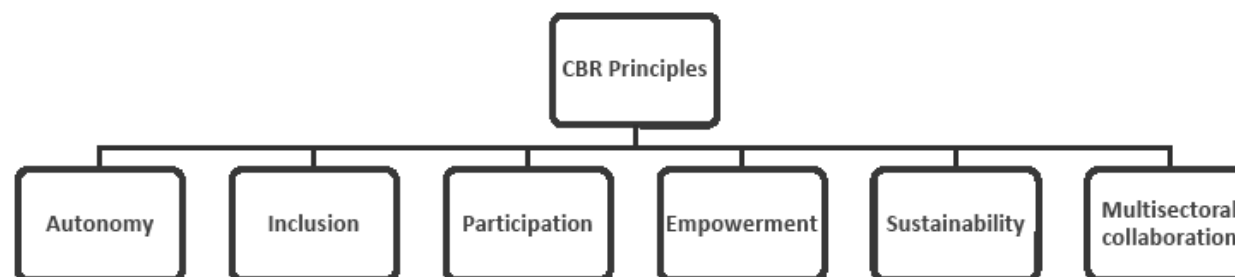
Option A: CBR program evaluations should be situated within the CBR Matrix.

- This would entail that evaluations should clearly state which elements of the CBR Matrix were evaluated. For example, one could report on: How has this program contributed to ensuring that people with disabilities had access to the assistive devices they needed? How has this program contributed to increasing wage employment opportunities for adults with disabilities?
- The desirable outcomes provided for each component and element of the Matrix in the CBR Guidelines could be used in conjunction with other relevant outcomes specific to the situation.



Option B: CBR program evaluations should be situated within the list of CBR principles.

- These are presented in the *CBR Guidelines* and are based on the *Convention on the Rights of Persons with Disabilities*, with the addition of empowerment and sustainability. We regrouped them in 5 categories. Since multi-sectoral collaboration is highly stressed in the CBR Guidelines as a key ingredient of CBR as a community-development strategy, we added it as a 6th principle.
- This would entail that evaluations should clearly state which CBR principles were evaluated. For example, one could report on: How has this program contributed to increasing the inclusion of people with disabilities? How has this program collaborated with stakeholders from various sectors to facilitate the participation of people with disabilities?



Option C: CBR program evaluations should be situated within a framework that combines the CBR Matrix and the CBR principles.

- This would entail that evaluations should clearly state which CBR elements and which CBR principles were evaluated. For example, one could report on: To what extent does this program contribute to increasing the participation of people with disabilities in recreation, leisure and sports? To what extent does this program facilitate the inclusion of people with disabilities in mainstream self-help groups?
- This framework may be more comprehensive than the two other choices above. However, it is also more complex and may therefore be harder to manage.

		CBR Principles					
		Autonomy	Inclusion	Participation	Empowerment	Sustainability	Multisectoral collaboration
CBR Matrix	Health - Promotion - Prevention - Medical care - Rehabilitation - Assistive devices						
	Education - Early childhood - Primary - Secondary & higher - Non-formal - Lifelong learning						
	Livelihood - Skills development - Self-employment - Wage employment - Financial services - Social protection						
	Social - Personal assistance - Relationships, marriage & family - Culture & arts - Recreation, leisure & sports - Justice						
	Empowerment - Advocacy & communication - Community mobilization - Political participation - Self-help groups - DPOs						

Please tell us whether you agree or not with each of these 3 options. Please select 'Strongly Agree' only once.

	Strongly Agree: This is my first choice.	Agree: This is not my first choice but I would use it if a larger proportion of the panel prefers it.	Disagree: I don't like this option.
<u>Option A:</u> The CBR Matrix alone is sufficient as a shared framework for CBR evaluations.			
<u>Option B:</u> The CBR principles alone are sufficient as a shared framework for CBR evaluations.			
<u>Option C:</u> The CBR Matrix AND the CBR principles should be combined into a shared framework for CBR evaluations.			

Please explain your choices.

You may also provide suggestions if you wish.

Thank you for your time and contribution!

Appendix J: Summary of Round 2 Findings

Findings from Round 2: CBR Program Evaluations

86% (36/42) of Round 1 panellists were also able to complete Round 2.

- Thank you so much!

Main comments and questions from the panel on Round 1 findings:

The panel is very credible!

- Most of you highlighted that the panel represents a well-balanced range of valuable perspectives in relation to geographical spread, roles in CBR and gender.

“The people whom I know on the panel are all people I have a lot of respect for because of their previous contributions to strengthening CBR. I assume those I do not know are also meaningful contributors.”

- Some highlighted that, ideally, even more representatives from certain regions, speaking different languages, and having a disability, would have been included.

How did we decide when consensus would be reached?

- One expressed that more negotiation and discussion might be needed for some elements and wondered how we determined that consensus would be reached.
 - Our 75% cut-off point for consensus was chosen beforehand and is consistent with the literature on Delphi studies (Diamond et al., 2014). This means that 75% or more needed to agree to say that the group reached consensus. Note that % who agreed were much higher than 75% for most elements.
 - We have tried to provide enough space for comments and to reflect back to you what others have suggested, but we acknowledge that face-to-face group discussions would have been helpful and this is certainly a limitation of our methodology. The main reason for which we have chosen this approach is to ensure that representatives of the CBR community from all around the world and playing different roles would be able to contribute.

3 raised questions on the most important criteria for CBR evaluations.

- You questioned the consensus associated with the most important criteria for sound CBR evaluations, either because you thought that all the seven suggested criteria were important or because you wondered how some people might not value highly inclusion and empowerment.
 - We acknowledge that choosing 3 out of 7 potentially important criteria was very challenging. We chose this strategy to try to identify criteria that should be emphasized. It does not mean that others are not important, but rather that efforts could be concentrated on elements ranked higher by the majority.

Congratulations!

You reached consensus on 8 new recommendations for sound CBR evaluation processes and methods in Round 2!

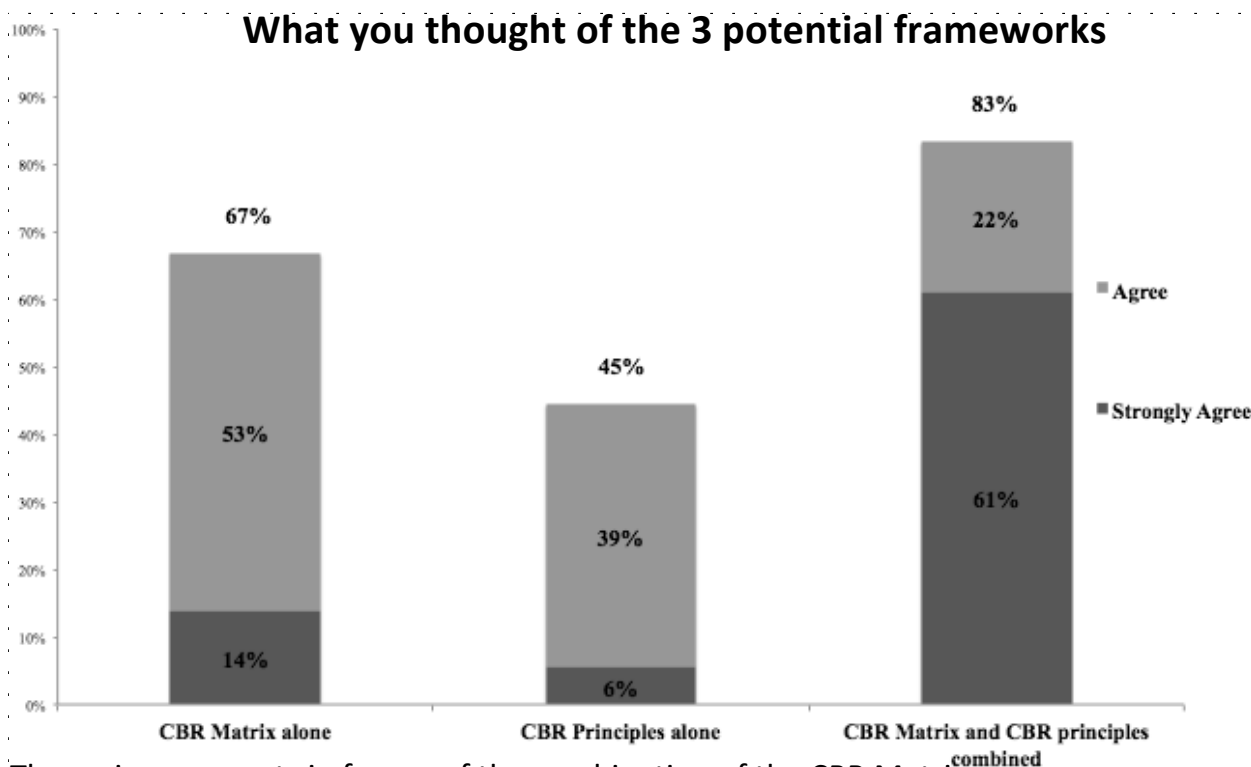
Very high agreement levels were found in Round 2 as **92% to 100% of you agreed** with the recommendations suggested for the evaluation process and methods. Most of those who disagreed suggested modifications to the recommendations and would very likely agree once their suggestions are integrated. Note that most of the changes proposed were associated with clarifying the circumstances under which the recommendations apply, the words used, and who key local stakeholders are, in the explanations following each recommendation.

How many agreed with the recommendations?

- | | |
|---|--------------|
| 1. The evaluation process should be designed in a way that will empower the local community, including people with disabilities. | 34/36 (94%) |
| 2. Evaluators should pay attention to the impact of cultural differences during a CBR evaluation and adapt as needed. | 34/36 (94%) |
| 3. Evaluators should strongly consider using participatory tools during CBR program evaluations. | 36/36 (100%) |
| 4. Evaluators should encourage and support monitoring of CBR programs. | 33/36 (92%) |
| 5. Evaluators should work closely with local stakeholders throughout the CBR evaluation process. | 33/36 (92%) |
| 6. As appropriate, findings should be shared locally and with other audiences to advance knowledge and contribute to CBR advocacy. | 36/36 (100%) |
| 7. CBR program evaluations should always translate into action . | 34/36 (94%) |
| 8. Strategies should be used to alleviate the impact of linguistic differences. | 36/36 (100%) |

You also reached consensus that CBR evaluations should be situated within a framework that combines the CBR Matrix and the CBR Principles! ... in a flexible way!

The shared framework would be used to define evaluation questions, choose outcome measures and situate findings when reporting results.



The main arguments in favour of the combination of the CBR Matrix (ILO, UNESCO, WHO, 2004) and CBR Principles (WHO, ILO, UNESCO, IDDC, 2010) included comprehensiveness and potential to demonstrate impact. The main arguments against were: empowerment appeared in both, principles were too summarized, and it appeared complex. Yet, others thought that it was not as complex as it may look!

"To look at both access and participation. (...) we may find PWDs [people with disabilities] will have access (eg had received an assistive device) but this may not reflect clearly on their participation level.", "It may look more complex, but the principles are not actually additional 'domains' but aspirations or principles to keep in mind.", "Examples can be provided to show that by taking only specific components of it, a CBR program can develop an evaluation process very relevant to its specific goals."

Other suggestions: 1) using the Joint Position Statement (ILO, UNESCO, WHO, 2004), 2) looking at whether inclusion with dignity was achieved for each element of the CBR Matrix, 3) leaving the choice open as to which of the CBR Matrix, the CBR Principles, or a combination of both, is most helpful for each situation.

- This study context prevents us from exploring these further. Thus, we decided to nuance our recommendation because we feel that further discussions are required. In the meantime, CBR evaluations can use the CBR Matrix and the CBR principles in a very flexible way and share their experience.

Recommendations for sound CBR evaluations

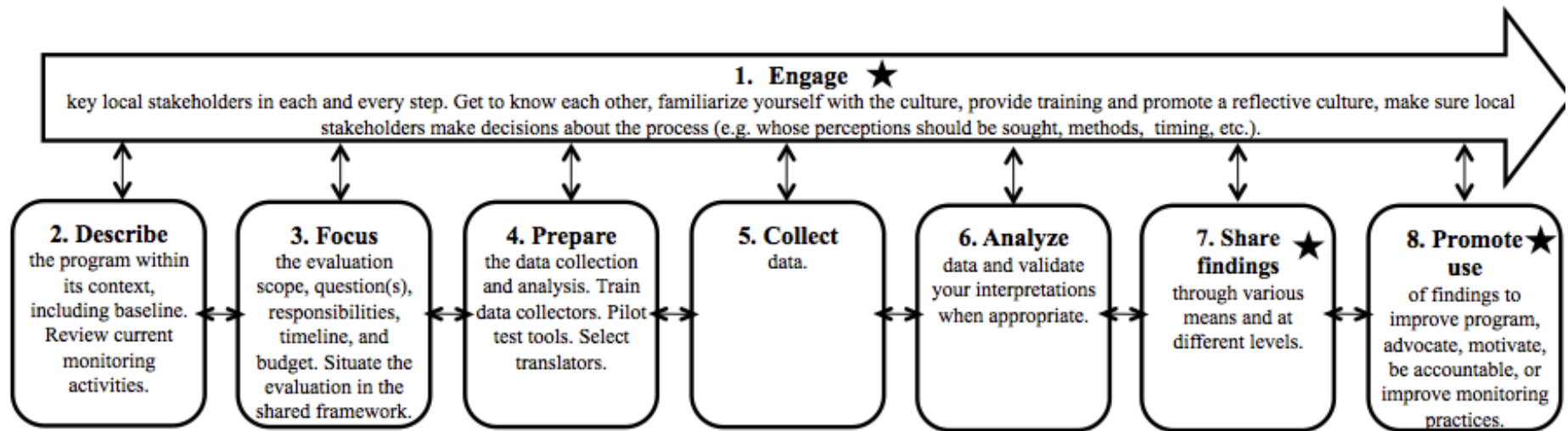
We have used your suggestions to improve the panel recommendations for sound CBR program evaluations. Changes made using the suggestions received in Round 2 are written in blue. Please note that changes in the explanations of each recommendation have also been made and will be available in Marie's doctoral dissertation.

	Recommendations
Characteristics of the evaluation process	1. Attempts should be made to include the voices of all relevant stakeholders in CBR program evaluations. 2. Wherever feasible, the evaluation process should be designed in a way that will empower key local stakeholders, including people with disabilities. 3. Evaluators should pay attention to the impact of cultural differences during a CBR evaluation and adapt as needed. 4. Evaluators should work closely with key local stakeholders throughout the CBR evaluation process. 5. Findings should be shared locally and with other audiences when appropriate to advance knowledge and contribute to CBR advocacy. 6. Evaluators should promote use of findings from CBR evaluations. 7. Whenever appropriate, external evaluators should make concrete recommendations in regard to monitoring of the CBR program targeted. 8. Strategies should be used to alleviate the impact of linguistic differences.
Characteristics of the methods	9. Mixed methods should be strongly considered when evaluating CBR programs. 10. CBR Evaluators should choose data collection tools that are fit for purpose (i.e. appropriate to the needs, culture, program, and resources, and have been tested whenever possible). Those can include context-specific and universal data collection tools. 11. As much as possible, one should combine universal and context-specific indicators when evaluating CBR programs. 12. Evaluators should strongly consider using participatory tools during CBR program evaluations.
Framework	13. CBR program evaluations should be situated within a shared framework. More discussion is needed to clarify the exact content of this framework, but it should combine the CBR Matrix (ILO, UNESCO, & WHO, 2004) and the CBR Principles (WHO, ILO, UNESCO, & IDDC, 2010) in a flexible way.

Based on our findings, we would like to suggest a potential list of steps that could guide CBR evaluations.

We acknowledge that this would need to be used with flexibility and complemented by tools to be most useful. Stars indicate steps that you thought needed to be emphasized. Since many of you suggested that engaging stakeholders in the whole process was essential, it is linked to each and every step!

Potential list of steps for CBR evaluations



Here are the names of our generous panellists (86% of which completed Round 2):

- Binoy Acharya, UNNATI Organization for Development Education, India
- Marieke Boersma, Light for the World, Ethiopia
- Svein Brodtkorb, Norwegian Association of Disabled, Norway
- Yinghong Cai, Handicap International, China
- Eva Yin-han Chung, Tung Wah College, Hong Kong
- Huib Cornielje, Enablement, Netherlands
- Israel Cruz, Universidad del Rosario, Colombia
- Sunil Deepak, AIFO, Italy
- Eduardo García, Piña Palmera Mexico
- Solangel Garcia, Red de RBC de las Américas, Colombia
- Brigitte Gautron, Consultant, Spain
- Priscille Geiser, Handicap International, France
- Ann Goerdts, New York University, USA
- Cindy Greer, Norwegian Association of Disabled
- Geraldine Halls, AIFO, Guyana
- Gulliver Ishmael, Sudan Evangelical Mission, South Sudan
- Djenana Jalovic, Queen's University, Canada
- Sally Hartley, University of East Anglia, United Kingdom
- Jorge Morales, CAMADDS AC, Mexico
- Chapal Khasnabis, WHO, Switzerland
- Pim Kuipers, Griffith University, Australia
- Jayanth Kumar, AIFO, India
- Jay Kumar, SAMA Foundation, India
- Gwynnyth Llewellyn, University of Sydney, Australia
- Sue Lukersmith, University of Sydney, Australia
- Malcolm MacLachlan, Trinity College Dublin, Ireland
- Ros Madden, University of Sydney, Australia
- Hasheem Mannan, Trinity College Dublin, Ireland
- Stephen Muldoon, Livability, Ireland
- Malcolm Peat, Queen's University, Canada
- Eladio Recabarren, Senadis, Chile
- Lieve Sabbe, UNICEF, USA
- Pedro Safrao, Light for the World, Mozambique
- Rachel Tainsh, Health Prom, United Kingdom
- Maya Thomas, Disability, CBR and Inclusive Development Journal, India
- Sara Varughese, CBM, India
- Wim van Brakel, KIT, Netherlands
- Andrea Vogt, Operation Mercy, Tajikistan
- Angela Wangda, Home Physiotherapy Service, Canada
- David Werner, Health Wrights, USA and Mexico
- Mary Wickenden, University College London, United Kingdom
- Victoria Zubiaurre, Servicio Nacional de Rehabilitacion Argentina