

Participatory inclusion evaluation: a flexible approach to building the evidence base on the impact of community-based rehabilitation and inclusive development programmes

Erik Post, Huib Cornielje, Karen Andrae, Anneke Maarse, Marguerite Schneider and Mary Wickenden

In response to the variability, complexity, and cross-sectoral nature of community-based rehabilitation (CBR) programmes and the lack of a structured approach to impact evaluations, an innovative model and set of tools, called the participatory inclusion evaluation (PIE) approach, has been developed. This is conceptualised in an evaluation framework, influenced by diverse evaluation theories and methods used in mainstream international development. Each has its own merits and shortcomings, so we have developed a hybrid to ensure a pragmatic and flexible mixed methods approach. We discuss the theoretical choices made in the evolution of PIE. PIE involves the participation of three types of stakeholders: people with disabilities, the CBR core team, and the network of strategic partners. PIE assesses the impact and the what, how and why of CBR programmes, privileging people with disabilities' perspectives. In synchrony with the UN Convention on the Rights of Persons with Disabilities (CRPD) principles and the World Health Organisation (WHO) CBR guidelines, impact is defined as changes in inclusion, empowerment, and living conditions. PIE was developed using a participatory process, piloted in Uganda and Malawi. It provides a flexible outcome and impact evaluation methodology for CBR, using a mixture of quantitative and qualitative data, using an inclusive and participatory approach.

Keywords: community-based rehabilitation; outcomes; impact; evaluation; participatory; evidence; Uganda; Malawi; conceptual models; framework; community; service delivery; empowerment; outcome mapping

Introduction

Over the past three decades, community based rehabilitation (CBR) has been promoted and practiced as a way to support people with disabilities (PWDs) in low resource settings. Informed by the era of more explicit human rights priorities and the production of

comprehensive guidelines promoting its multi-sectoral, inclusive aims (UN 2007, WHO 2010), CBR has evolved over time and is now operationalised in many middle and low income countries, in various guises. However, the question of how to evaluate its worth has remained elusive. Anecdotally it is reported as successful but systematic, comprehensive and inclusive processes to explore how well, how and why it works have not been established. Evaluation of these kinds of questions is challenging, but capturing the outcomes and impact of CBR on people's lives is even more so. It is agreed by many that there is a lack of clear guidance and applicable tools for both ongoing monitoring and more intermittent evaluation of what happens in CBR programmes and how they are experienced by PWDs themselves (Lukersmith et 2013, Grandisson et al. 2014, Iemmi et al. 2016).

In response to the lack of structured and comprehensive models or formats for evaluating the outcomes and impact of CBR programmes, we have developed the participatory inclusion evaluation (PIE) approach during a two and a half year iterative process, including piloting of draft versions in four sites in Uganda and Malawi. We describe here some conceptual and theoretical dilemmas in evaluation practice generally, for CBR, and in the development of PIE. We argue for this approach's potential usefulness and relevance in collecting clear evidence about how and why CBR works and how it impacts the lives of people with disabilities and their families. Importantly, better outcome and impact evaluation, using a more systematic comprehensive approach, would not only inform future interventions but also enable useful comparison across time and between programmes at the local, regional or international level. If CBR is the best way to support PWDs at community level, we need to be able show this clearly so that others can build on this success.

The following background section presents an overview of the choices available in approaches to evaluation in international or community development contexts. We discuss particularly the pros and cons of theory-based and participatory evaluation philosophies. We also consider the need for mixed methods, incorporating existing monitoring data, as well as both quantitative and qualitative evidence collected in inclusive ways from a wide range of stakeholders who are involved in the lives of PWDs. An overview of CBR evaluation dilemmas shows the need for a shift in focus from inputs and output measurement to outcomes and impacts in order to inform the future.

It is beyond the scope of this article to describe in detail the PIE pilot testing itself or the details of the evaluations' findings. These will be published separately. This article provides an overview of the theoretical dilemmas encountered and choices we made while developing PIE. It argues the need for a structured but flexible approach to CBR evaluations focussing on outcomes and impact, and the use of a range of complementary and participatory, mixed (quantitative and qualitative) methods to gain an in-depth and nuanced view of what a CBR programme is doing.

Evaluation of CBR

CBR is defined as a multi-sectoral strategy for rehabilitation, equalisation of opportunities, poverty reduction, and social integration of people with disabilities (WHO 2004). It is characterised by its varied approaches in providing community support for disabled people, playing a decisive role in policy development, and determining the support needed at community, family, and individual levels. CBR programmes work for the benefit and development of the whole community, encouraging inclusive development, fostering empowerment and emphasising the realisation of human rights for all (Finkenflügel et al. 2008).

In 2010, the World Health Organisation (WHO), the International Labour Organisation (ILO), the UN Education, Scientific and Cultural Organisation (UNESCO) and the International Disability and Development Consortium (IDDC) jointly published the 'Community-based rehabilitation guidelines', including the previously published 'CBR Matrix' which lays out five potential key components of interventions broadly linked to different sectors: health, education, livelihood, social participation, and empowerment (WHO et al. 2010). Each of these components is divided into five key elements. This is useful for categorising programme activities and guiding programmes and has probably strongly influenced the way programmes structure their work in the last decade.

However, despite its nearly 30 years of history, there is no agreement on how CBR should be evaluated (Grandisson et al. 2014, Kuipers et al 2008, Wirz & Thomas 2002). An early effort at providing a systematic evaluation framework by Wirtz and Thomas (2002) focused on three domains: maximising the potential of disabled persons, service delivery, and the environment. Shifts in the conceptualisations of CBR from a biomedical to a multi-sectoral human rights and equity orientation did not result in the production or adoption of a standardised or structured evaluation method. These changes did, however, stimulate demand for a much wider range of criteria to show effectiveness and impact (Finkenflügel et al. 2008). Despite this progress, evaluation of CBR programmes remains a challenge. Programmes are usually multi-sectoral which means that combinations of factors can affect outcomes and impact at multiple levels: for disabled people, their families, and at community level. For example an awareness-raising programme for service providers such as health and education workers, may change their attitudes and practice in multiple but subtle ways. PWDs may report changes in the way they are treated but may not be able identify why or how this has come about.

Given that a fundamental principle of CBR is that it should be inclusive and should share power and control with PWDs, it seems axiomatic that evaluation of CBR should also be participatory, inclusive and equity focussed. To date, most CBR evaluations have not

involved disabled people, the wider community or CBR workers sufficiently (Kuipers & Harknett 2008). This oversight contradicts CBR principles of participation and empowerment. The various stakeholders involved in CBR projects are conceptualised well in models like the Innovative Care for Chronic Conditions (WHO 2002). In this model, outcomes at the level of disabled people and their families are influenced by community actors and service providers, taking the local context into account. The complexity and heterogeneity of CBR programmes calls for the development of new tools and guidelines for monitoring and evaluation (Lukersmith et al. 2013). The voices of people with disabilities are essential to any research or evaluation aiming to inform the planning of services. These voices can also help develop new approaches to evidence-based research and practice (Kuipers & Harknett 2008). In the next section, we consider lessons from current approaches to evaluation which we took into account when designing a new approach to evaluation of CBR.

Learning from evaluation approaches

Evaluations of international or community development interventions are driven by a variety of needs: accountability to donors, the public, partners, and beneficiaries, to determine the success of those interventions, to understand how the intervention affects people and to understand how positive changes can be maximised. However, evaluations can provide evidence and shed light on programmes in a range of ways. Definitions of success and approaches to demonstrating it vary in the development sector. Some approaches assume linear relationships between inputs (what was done), outputs (what happened) and outcomes (what the result was), but few attempt to explore the impact on people.

Impact can be evaluated quantitatively or qualitatively (or both), but either way will tell us about how the beneficiaries' lives have changed in tangible ways, e.g. increased ratings on quality of life, or stories about feeling more included in community events. Evaluations should also tell us how things might be done better (e.g. more efficiently or effectively) (O'Flynn 2010). These different foci are not always compatible or achievable using 'conventional' (i.e. linear) programme logic and predominantly quantitative measurement. Aiming to balance accountability and learning needs necessarily shifts the focus towards outcomes and impact and to exploration of complexity, rather than assuming linear causal relationships between what is done and how it is experienced by the beneficiaries. In addition to the measurement purely of quantitative inputs and outputs, policymakers and funders increasingly demand analyses of the *how* and *why* of programme effectiveness, to inform future actions (Stern et al. 2012).

Impact evaluations aim to answer questions about the 'real' effect of interventions and the extent to which changes can be attributed to a specific intervention (Savedoff et al. 2005).

They require dialogue with all relevant stakeholders to clarify and define scope and purpose (Ramalingam 2011). Australian Aid defines impact evaluation as:

A systematic and empirical investigation of the impacts produced by an intervention - specifically, it seeks to establish whether an intervention has made a difference in the lives of people. It aims to answer questions about what works or does not work, how, for whom and why. (Australian Aid 2012: 2)

Rigor in evaluation, including in impact evaluation, has rightly gained increasing prominence and requires answers to questions regarding who is responsible for the change happening, that is attribution (World Bank 2011). In most development programmes, however, so many factors influence processes of change that it is often difficult to attribute particular changes to specific interventions or agents directly. Change often happens indirectly and is mediated through a variety of stakeholders and routes. Thus a direct linear causal pathway between inputs, outputs, outcomes and impacts is not demonstrable or realistic to pursue. This has led to a preference for establishing 'contribution' or 'plausible association' rather than attribution (White 2009). Increasingly, the complex and recursive interactions between context and interventions are recognised as being responsible for non-linear chains of causality and unexpected events, challenging conventional logical framework thinking which is often found to be overly reductive (Garcia & Zazueta 2015). The related concept of 'complicatedness' implies multiple components, agencies, and causal strands, whereas 'complexity' refers to situations that evolve continuously, creating new conditions forming the basis for further development and results. In complex situations, causality can only be seen retrospectively. Interventions that have both complicated and complex characteristics are challenging, as the variable path to success is not predictable (Rogers 2008). Despite criticisms that theory based evaluations over-simplify 'complex' processes (Blamey & Mackenzie 2007, Rogers 2008), various theory-based evaluation tools are used in specific contexts to demonstrate change and causality. Among these are theories that pay considerable attention to context whereas others aim to identify clusters of similar outcomes to determine causation (Barnett & Munslow 2014).

A mixed methods approach to evaluation offers a way to overcome the limitations and time constraints of either purely qualitative or quantitative methods and demonstrates the benefits of a triangulated approach (Hartley and Muhit 2003). Using mixed-methods, seeming loss of statistical rigor (where large enough sample sizes are often not possible) is outweighed by collecting 'small-n' participatory statistics' such as people's votes or rating scales about an intervention, in combination with systematically collected qualitative experientially based data on why and how interventions do or don't work. This multi-pronged approach is particularly compelling in evaluating complex systems and interventions which aim to prioritise community involvement (IDRC 2004).

Participatory evaluations are based on the understanding that change and impact must integrate ideas of participation, transparency, empowerment, accountability and partnership (Stern et al. 2012). However, participatory methods of evaluation are surprisingly still underdeveloped, although this is changing. Participatory methods are often assumed to be purely qualitative and are under-estimated in relation to their potential for generating numbers (Chambers et al. 2009). However, there has been recognition of the power of ‘participatory statistics’ where useful quantitative data can be generated at community level (Holland 2013). Among well-known participatory models and tools is participatory impact assessment (PIA) which uses participatory tools and combines them with statistical methods, to measure impact (Catley et al. 2007), and most significant change (MSC), a tool which collects impact related stories and facilitates consensus-making about what is important across a group of stories (Davies et al. 2005). Sensemaker®, another impact evaluation method, analyses the significance of what has changed from the storytellers’ perspectives, using pattern detection software (Snowden 2016). The method has both qualitative and quantitative elements, but is often seen as too expensive for small or even mid-size organisations (Deprez et al. 2012). An elegant method for assessing the impact of a range of development programmes is the Participatory Assessment of Development (PADEV) tool, which was piloted in a number of countries (Dietz et al. 2013). PADEV uses nine short, participatory exercises to elicit what a variety of stakeholder see as changes in their lives (as a result of an intervention) and their relative importance.

An approach which deliberately contrasts itself with theory-based evaluation is outcome mapping (OM) which ‘characterises and assesses the contributions made by development projects, programmes or organisations to the achievement of outcomes’ (Earl et al 2001, p.8). OM acknowledges the complexity of programmes and recognises the essential role of people and organisations in processes of change, engaging with them to enhance understanding of motivation, roles, relationships, and value systems in bringing about concrete changes (Smith et al. 2012). Originally conceived as an approach for programme planning, OM is increasingly being adapted for evaluation purposes. Through reflection and interaction, OM promotes accountability of stakeholders and partners, and fosters ownership in a collective way. Whereas evaluations based on predominantly logic-based frameworks pay less attention to innovation and learning, OM offers a flexible approach and does not necessarily expect straightforward and linear relationships between inputs, outcomes, and impact (Jones & Hearn 2009). A good complement to OM is the 5-capabilities assessment, which helps implementing organisations to reflect on their capabilities to “act and commit”, “deliver on development objectives”, “adapt and self-renew”, relate to external stakeholders”, and “achieve coherence” (Keijzer et al. 2011).

Overall, then it can be seen that there are a number of dilemmas in choosing an approach to carry out evaluation. These dilemmas also relate to CBR programmes. Different evaluation approaches either try to reduce or alternatively embrace and explore complexity, and they are

participatory to different degrees. Choices made will reflect the underlying aims of programmes and assumptions about how change happens (whether explicitly called a theory of change or not), as well as the preferences of funders or commissioners of evaluations. The key purpose of the evaluation may be to assess the programme from a financial viewpoint (cost effectiveness or value for money), to reveal how the programme works, whether it could be scaled up or improved and/or to show upward and/or downward accountability.

Conceptual model for participatory inclusion evaluation

The project described here set out to respond to the need for a structured but flexible approach to evaluation of CBR, focussing predominantly on outcomes and impact and using mixed methods. Based on over two and a half years of collaborative work, we developed a conceptual model and a set of tools to structure the evaluation process, eventually summarised in an evaluation framework, namely participatory inclusion evaluation (PIE). The model aimed to provide some uniformity and guidance about the different stages in carrying out an impact evaluation of CBR and similar inclusive development programs. Initial consultations with representatives from major international non-governmental organisations (INGOs) working in disability during the proposal writing stage, affirmed the need for development of systematic impact evaluation methodologies and tools. Guidance in the WHO CBR guidelines about monitoring and evaluation were felt to be too generic and not to provide enough practical assistance to support CBR managers or independent evaluators to carry out in-depth evaluation.

A review of relevant evaluation theories summarised above led us to develop a conceptual model for CBR evaluation. We drew initially on the Innovative Care for Chronic Conditions model (WHO 2002), and subsequently on outcome mapping. The latter's advantages are the focus on the essential role of people in facilitating change and in exploring how different actors or stakeholders make change happen, principally by looking at changes in behaviour. Having also identified a need to make the process as inclusive and participatory as possible, we considered all the possible informants who would ideally be consulted and drew up a list of candidate methods and tools which might be useful. Those identified as of most potential use were: most significant change (Davies et al 2005), Sensemaker (Snowden 2016), the five capabilities (Keijzer et al. 2011), participatory assessment of development (PADEV) (Dietz et al. 2013), as well as standard qualitative data collection methods such as visualisations, mapping, ranking, individual interviews and focus group discussions. Based on the analysis of the different approaches, we arrived at a combination to match the different groups of informants' interests, skills and preferences, aiming to be as participatory and inclusive as possible.

Using a hybrid collection of tools to focus on outcomes and impact we aimed to assess the perspectives of a triad of three distinct types of stakeholders, although the exact membership of each will vary:

- People with disabilities (various types of impairments, genders, ages) and their families, allies and organisations
- The CBR core team: managers, staff and volunteers
- The network of strategic partners: service providers, community organisations and other agencies actively involved in disability or inclusion work

We set out to collect the data and structure the analysis and reporting with reference to the five CBR matrix components (or whichever are relevant in a programme) and also in relation to the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the CBR guidelines. The aim was to design a set of participatory tools which would be able to evaluate the outcomes, and impact, of CBR programmes. In addition to evaluating PWDs perspective on how a programme is affecting them, we wanted to evaluate key aspects of programme functioning and performance which are often included in evaluation methodology (Chianca 2008):

- relevance (incorporating coverage and equity)
- efficiency
- effectiveness (incorporating quality and access)
- sustainability

It was imperative that the tools were structured but flexible and facilitate building knowledge of complex dynamics in programmes rather than assuming simple linear relationships between activities, inputs, outputs and impact.

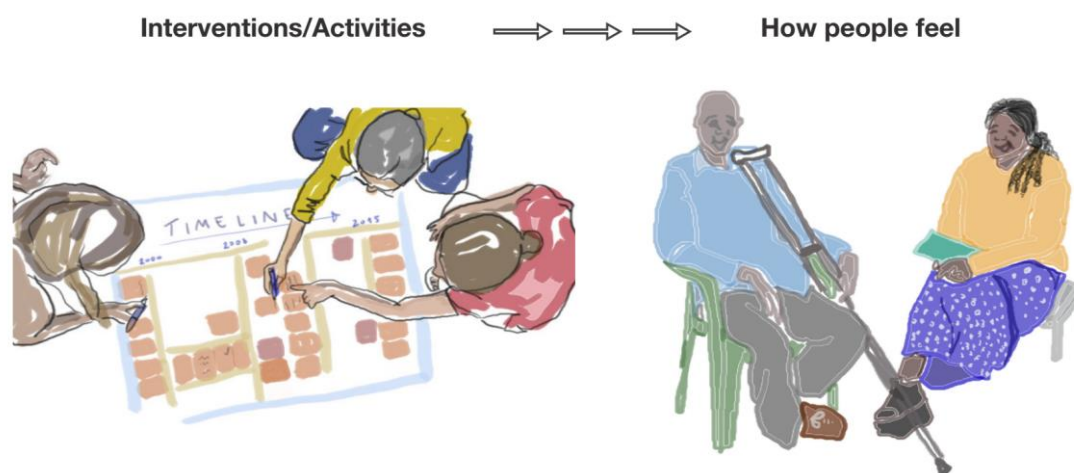


Figure 1: Measuring impact in people's lives is what matters

The application of the above mentioned principles, and the identification of the role of the key players in the ‘triad of stakeholders’, facilitates the applicability of the approach for any CBR programme, and aims to make evaluations comparable in principle, even if they vary in details. We aim to assess *what* is going well (or not), and explore *how* and *why* that is, with a strong focus on the perspectives of people with disabilities and their families (Figure 1). Fundamental in what is being evaluated is the relationships between this triad of stakeholders and how they influence each other to bring about change in the lives of PWDs. PIE explores the complexity of CBR with its (usually) multi-agency, cross-sectoral characteristics (Figure 2).

Overview of the structure of PIE

PIE consists of a 7-stage participatory process with detailed formats and instructions for tools in each stage (Table 1) as described in an online handbook (Wickenden et al. 2016). CBR evaluators can select from the tools those that are most relevant to their evaluation context and task. A detailed description of how the tools evolved and their final format is not appropriate here and will be presented in other publications. A comprehensive PIE process will take up to two weeks of fieldwork and 3-4 weeks of analysis and reporting time. We envisage such a detailed process would only be done every 3-5 years. Thus this is the suggested time period for review of the programme (e.g. questions often ask ‘what has changed in the last 3-5 years’).

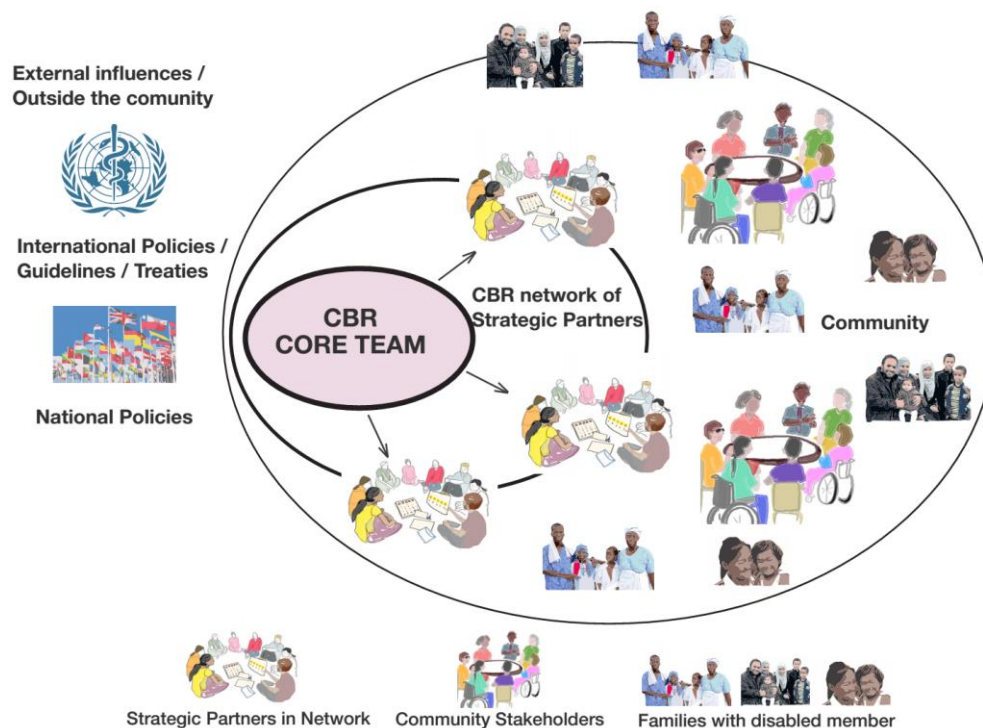


Figure 2: The CBR network is linked to community and policies

Table 1: Stages and tools for participatory impact evaluation

Stages	Tools/Tasks
Stage 1: Preparation, Planning, Getting an overview: Situation analysis	<ul style="list-style-type: none"> Initial meeting with Core Team Situational analysis with key informants Big mapping of local area Timeline of disability and CBR activities Stakeholder Mapping (network of Strategic Partners) <ul style="list-style-type: none"> Document review – of existing monitoring and previous evaluation documents etc. Identification of informants -Planning consultations
Stage 2: CBR Core Team perspectives	<ul style="list-style-type: none"> Individual interviews with CBR manager/s Focus group discussion with CBR core team Team self-assessment: 5-Capabilities Tool
Stage 3: Listening to Groups of Strategic Partners	<ul style="list-style-type: none"> Focus group discussion (or individual interviews) (4-6)
Stage 4: Listening to people with disabilities & carers	<ul style="list-style-type: none"> Individual interviews PWD, parents/carers (15-20) Focus groups discussions PWD/Disabled People’s Organisations (DPO), parents/carers (4-6) Focus groups with disabled children/youth (1-2) Tools include visual methods e.g. Identification of CBR matrix components using photos, Emoticon ‘smiley faces’ to rate satisfaction with services, (group and individual ratings)
Stage 5: Initial analysis: Data summaries and preliminary findings	<ul style="list-style-type: none"> Various data collection and summary tools Summarising/sorting/entering data in excel workbook
Stage 6: Community meeting: validation of findings and future planning	<ul style="list-style-type: none"> Presentation by evaluator(s) of key findings Exercises and group work to generate:- Reflection/validation of provisional findings Recommendations and action plans for future
Stage 7: Summarising, presenting and reporting the PIE evaluation findings	<ul style="list-style-type: none"> Suggested report format – linked to the evaluation framework – prompting reporting in relation to 5 CBR components and by Impact, Effectiveness, Efficiency,

The inclusive design of PIE facilitates reflection of diverse opinions and perspectives from the triad of stakeholders referred to previously. Of great importance in the PIE approach is the final community validation meeting with all stakeholders (stage 6, see Table 1), during which the provisional evaluation findings are validated, recommendations are made, and future plans

outlined. Again the suggested format is OM inspired. A structured reporting format helps the evaluation team to report in a concise and consistent way, facilitating comparison across time and programmes.

Pilot evaluations using the draft model and tools in Uganda and Malawi

Teams of three local evaluators were employed to carry out pilot evaluations using draft versions of the model and set of tools. Teams were gender mixed and each included one person with a disability. The teams were supported by the international research team and in-country logistical partners, comprising the National Union of Disabled Persons of Uganda (NUDIPU) and the Ministry of Gender in Uganda and the Malawi Council for the Handicapped (MACOHA) in Malawi, as well as by in-country advisory committees of local experts in disability, CBR and evaluation.

Initially, draft versions of the model and tools were prepared by the core international research team. These were by no means seen as final but provided a basis for discussion and development during the first preparation/development workshop held in Kampala with Ugandan and Malawian colleagues. The draft tools were tested out in role-plays, translated and finalised for the first pilot which followed immediately, the teams being supported by the research team in the field in both countries.

The pilot evaluations took place in two phases:-

Phase 1: Kayunga, Uganda and Machinga, Malawi - simultaneously

Phase 2a: Kasese Uganda and 2b Mzimba, Malawi – 3 months apart

During an interval of 9 months between phases, an extensive review, revisions and refining were carried out to the model and tools in the light of the feedback at an analysis workshop after Phase 1, discussion with in-country teams and advisory committees, and with the international team. Creative conversations tried to resolve the aspiration for a theoretically coherent approach and the demands for a practical and do-able process which would be used in the real world. As the two pilots in phase two were also separated in time, there was opportunity for further minor revisions and developments to the tools at this stage.

A number of fundamental changes and reiterations arose from the analysis workshops. For example:-

- 1) Conceptualisation of ‘impact’ in the CBR context- after some discussion and thematic analysis of data from Phase 1 it was decided to define impact as broadly being expressed as changes in 3 distinct aspects of life: Inclusion, Empowerment and Living Conditions.

These were further specified and described to give the evaluators guidance on how to ask targeted questions and to analyse their responses accordingly. These aspects reflect the UNCRPD principles (United Nations 2007) and the WHO CBR guidelines (WHO et al. 2010)

- 2) Clarification of terminology describing the 3 types of stakeholders to be consulted. In Phase 1, we used the OM term ‘boundary partners’ but found this caused confusion. We therefore retained the OM inspired idea of nested ‘circles of influence’ (see figure 2 above) but renamed the 3 types of stakeholders: CBR Core Team (usually a manager plus their staff and or volunteers), Strategic Partners (instead of boundary partners, these are a number of different agencies including service providers, advocacy groups, community, faith-based groups etc. who are actively involved in working with or for PWDs and with the CBR Core Team), and thirdly PWDs and their families and organisations (DPOs) in the community. This made it easier to see that an evaluation needs to explore the perspectives and contributions of all 3 groups and the way that they work together to bring about change.
- 3) Development and revision of the original evaluation framework. (See the final version in appendix). This visualisation gradually evolved to represent the types of data to be sought from the 3 different stakeholder groups, the tools to be used in each case and the ways that this data could be categorised and analysed. In combination with Fig 2 above, this provided the evaluators with a clearer understanding of what kinds of evidence they needed to collect.
- 4) Evaluation teams in Phase 1 identified a need for more detailed guidance and structure for the validation meeting, the analysis process and for reporting. Before Phase 2, these guidance documents were developed and so were trialed for the first time in 2a and then revised again before 2b.

Detailed description and discussion about the development of the individual tools and the finding from the 4 pilot evaluations will be published elsewhere.

Usefulness of evaluation tools

PIE was refined over the two and a half year period in response to the feedback from the evaluation teams, reviewing the data and the resulting reports. Participation and commentary was also invited from the advisory committees in each country and the four host CBR managers. A summary of lessons learned is provided below.

- A clear description of the structure and process helped evaluators with planning and prioritising focus areas for the particular programme being evaluated.
- The combination of tools facilitated collection of specific and triangulated perspectives from the triad of stakeholders
- The participatory and visual methods were favourably received, producing rich and meaningful data.
- Consulting with excluded groups that are usually overlooked, was perceived as positive, fun, surprising and interesting, although it continued to be a challenge
- Detailed data, collected directly from people with disabilities, was seen as a strength of the PIE approach. The tools enabled in-depth investigation of the outcomes and impact of CBR from a variety of perspectives compared to previous evaluations conducted by the teams.
- The community validation meetings were very positive events, with considerable appreciation about sharing of and consultation about the findings, meeting others and contributing to recommendations and future planning
- Use of the PIE evaluation framework helped evaluators to remain focussed on different aspects of the evaluation, consulting with the triad of stakeholders and with structuring planning, data collection, analysis, validation, and reporting
- The evaluation process stimulated renewed awareness and interest in the CBR programme in multiple stakeholders in the evaluation areas
- The evaluators themselves expressed having learned new perspectives on and understandings about disability, CBR and what to look for during evaluations.

Realities to note:

- Individual interviews with PWDs and focus group discussions with strategic partners can be time-consuming
- Collecting existing and ongoing statistics about the evaluation area and the CBR programme, monitoring data and documentary evidence is included as part of the process but is often incomplete or difficult to access
- Evaluators need clear guidance about accurate recording of quantitative/qualitative responses
- Evaluators need a clear understanding about what constitutes a Strategic Partner as opposed to a less involved community stakeholder, to facilitate systematic decision making about who to consult
- Sampling people with disabilities for individual interviews needs to be as inclusive as possible, ensuring capturing the perspectives of those with all impairments, both genders and all ages and situations
- Recognition of possible biases: recruitment of respondents, bias by CBR core team and strategic partners when engaging in self-rating

- A need for strong guidance about the analysis process. The evaluators often lacked confidence in summarising and interpreting the data and in how to use it effectively in the report.
- An in-depth participatory mixed methods evaluation process is demanding of resources: money, time and human effort.

Most of these points were addressed during Phase 1 and again during Phase 2. Some needed further attention in the final editing process of the handbook and tools and some are still not yet adequately resolved. We anticipate that further modifications of PIE will emerge as we learn from evaluators how well it works. A persistent dilemma throughout the project was achieving a balance between providing a robust structure for the process and maintaining the need for flexibility and creativity to suit different settings.

Conclusions and recommendations

Impact evaluation has various definitions and theoretical roots, and emphasis varies widely in terms of requirements for comparability, establishing causality and attribution. In the context of complex community interventions, causality and contribution analysis is challenging and is often not achievable or even desirable. Evaluations must then focus on the variety of factors influencing outcomes and impact in a particular context. Interventions often happen via a network of strategic partners who contribute directly or indirectly to bringing about change. The effects of interventions in different sectors can be recursive and multidimensional and thus notoriously difficult to disentangle.

CBR is a good example of a complex, multi-sectoral, multi-agency set of interventions with a relatively small and dispersed population and with the added complications of focussing on an excluded minority in society. If a CBR programme is following the model suggested by the WHO CBR guidelines that it should be focussed on realisation of the rights of PWDs in inclusive communities, then identifying directly measurable, easily isolated linear effects of it is almost impossible. Therefore, the absence of standardised evaluations is understandable. There is, however, agreement that CBR evaluation approaches need to become more rigorous, better documented, disseminated and shared. The PIE approach offers such structured way to gain insight into the outcomes and impact of inclusive development interventions on the lives of people with disabilities. PIE can usefully complement short-term monitoring and purely quantitative evaluation methodologies.

Participatory, inclusive approaches using mixed methods for outcome and impact evaluations are indicated for CBR and need to support and synchronise with the principles of CBR (WHO 2010) and the UNCRPD (UN 2007). The development of quantitative indicators for the wellbeing of people with disabilities, such as the recent WHO initiative (WHO 2015) are

welcome, as would be more cost-effectiveness studies. The use of these alongside an evaluation approach like PIE could provide a comprehensive view of the work that CBR does.

Information derived from systematic in-depth outcome and impact evaluations can form the missing link in advocating and lobbying governments to adopt CBR as a complementary approach to ensure more and better inclusion of people with disabilities in all domains of life. Inclusive development in all sectors is essential if the aspirations of the UNCRPD are to be realised. It is anticipated that the PIE model and tools will facilitate more uniform and comparable CBR evaluations and will help governments, INGOs and NGOs to focus their evaluations on outcome and impact. This focus will help to generate better insight into the importance of CBR as a strategy to support people with disabilities particularly in under-resourced and remote settings globally.

Acknowledgements.

The research project, which developed the PIE approach, was funded by a research grant from the Australian government aid programme (DFAT) (ADRA 2012).

Many thanks for their support and collaboration to:

In Malawi: MACOHA, Steven Msowoya, Margaret Wazakili, Peter Ngomwa, Sebastian Katamula, Jackson, Aron Mpondera, George Chiusiwa, Lyness Manduwa, Mercy Thawe, Dorothy Chinguo, Emmie Chiumia, Alistair Munthali

In Uganda: NUDIPU, Ministry of Gender, Collins Kafeero, Queen Asiimwe, Alice Nganwa, Carolyn Maholo, Barbara Batesaki, Agnes Nampeera, Priscilla Nkwenge, Joel Kawunguzi, Sylvia Biira, Kristie Oroma

International advisors: Joerg Weber, Priscille Geiser, Beatriz Miranda, Ton Dietz

Norwegian Association of the Disabled (NAD) for logistical support.

Fiona Budge for her great help in editing this article.

References

- Australian Aid, 2012. *Impact Evaluation, A Discussion Paper for AusAID Practitioners*, Available at: <https://dfat.gov.au/aid/how-we-measure-performance/ode/Documents/impact-evaluation-discussion-paper.pdf>.
- Barnett, C. & Munslow, T., 2014. *Process Tracing: The Potential and Pitfalls for Impact Evaluation in International Development. Summary of a Workshop held on 7 May 2014*, IDS. Available at: <http://opendocs.ids.ac.uk/opendocs/handle/123456789/5465> [Accessed April 18, 2016].
- Blamey, A. & Mackenzie, M., 2007. Theories of change and realistic evaluation: peas in a pod or apples and oranges? *Evaluation*, 13, pp.439–455.
- Catley, A. et al., 2007. *Participatory Impact Assessment A Guide for Practitioners*
- Chambers, R., Karlan, D. & Ravallion, M., 2009. Designing impact evaluations: different perspectives. *International Initiative for Impact Evaluation*, 4(July), pp.1–34.
- Chianca, T., 2008. The OECD/DAC Criteria for International Development Evaluations : An

E. Post, H. Cornielje, K. Andrae, A. Maarse, M. Schneider and M. Wickenden. 2016. Participatory inclusion evaluation: a flexible approach to building the evidence base on the impact of community-based rehabilitation and inclusive development programmes. *Knowledge Management for Development Journal* 11(2): 7-26
<http://journal.km4dev.org/>

- Assessment and Ideas for Improvement. *Journal of MultiDisciplinary Evaluation*, 5(9), p.11.
- Davies, R. et al., 2005. *The “Most Significant Change” (MSC) Technique, a Guide to Its Use*, Available at: <https://www.kepa.fi/tiedostot/most-significant-change-guide.pdf>.
- Deprez, S. et al., Vredeseilanden, 2012. *“The use of Sensemaker for measuring, learning and communicating about smallholder farmer inclusion (Case Report).”*
- Dietz, T. et al., 2013. *PADev guidebook: participatory assessment of development*, KIT Publishers. Available at: http://www.padev.nl/other_output/PADev_guidebook_2013.pdf.
- Earl, S., Carden, F. & Smutylo, T., 2001. *Outcome mapping: building learning and reflection into development programs*, International Development Research Centre. Available at: http://www.idrc.ca/en/ev-26586-201-1-DO_TOPIC.html.
- Finkenflügel, H., Cornielje, H. & Velema, J., 2008. The use of classification models in the evaluation of CBR programmes. *Disability and rehabilitation*, 30(5), pp.348–54.
- Garcia, J.R. & Zazueta, A., 2015. Going beyond mixed methods to mixed approaches: A systems perspective for asking the right questions. *IDS Bulletin*, 46(1), pp.30–43..
- Grandisson, M., Hébert, M. & Thibeault, R., 2014. A systematic review on how to conduct evaluations in community-based rehabilitation. *Disability and rehabilitation*, 36(4), pp.265–75.
- Holland, J., 2013. *Who Counts? The power of participatory statistics | Participatory Methods*, Rugby: Practical Action Publishing Ltd. Available at: <http://www.participatorymethods.org/resource/who-counts-power-participatory-statistics>.
- IDRC, 2004. *Addressing the Question of Attribution in Evaluation*, Available at: [http://www.outcomemapping.ca/download/admin_en_Addressing the Question of Attribution in Evaluation.pdf](http://www.outcomemapping.ca/download/admin_en_Addressing%20the%20Question%20of%20Attribution%20in%20Evaluation.pdf).
- Iemmi, V. et al., 2016. *Community-based rehabilitation for people with disabilities, 3ie Systematic Review Summary 4*, London. Available at: <http://disabilitycentre.lshtm.ac.uk/files/2014/07/Community-based-rehabilitation-for-people-with-disabilities-in-low-and-middle-income-countries.pdf>.
- Jones, H. & Hearn, S., 2009. *Outcome mapping: A realistic alternative for planning, monitoring and evaluation*,
- Keijzer, N. et al., 2011. *Bringing the invisible into perspective: Reference document for using the 5Cs framework to plan, monitor and evaluate capacity and results of capacity development processes*, Maastricht. Available at: <http://ecdpm.org/wp-content/uploads/2011-5Cs-Framework-Plan-Evaluate-Monitor-Capacity-Development-Processes.pdf>.
- Kuipers, P. & Harknett, S., 2008. Guest editorial. Considerations in the quest for evidence in community based rehabilitation. *Asia Pacific Disability Rehabilitation Journal*, 19(2), pp.3–14.
- Lukersmith, S. et al., 2013. Community-based rehabilitation (CBR) monitoring and evaluation methods and tools: a literature review. *Disability and rehabilitation*, 35(23), pp.1941–53..
- O’Flynn, M., 2010. *Impact Assessment: Understanding and assessing our contributions to change*, Available at: <http://www.intrac.org/data/files/resources/695/Impact-Assessment-Understanding-and-Assessing-our-Contributions-to-Change.pdf>.
- Ramalingam, B., 2011. *Learning how to learn: eight lessons for impact evaluations that make a difference*, Available at: <http://www.odi.org.uk/resources/docs/7096.pdf>.

E. Post, H. Cornielje, K. Andrae, A. Maarse, M. Schneider and M. Wickenden. 2016. Participatory inclusion evaluation: a flexible approach to building the evidence base on the impact of community-based rehabilitation and inclusive development programmes. *Knowledge Management for Development Journal* 11(2): 7-26
<http://journal.km4dev.org/>

- Rogers, P.J., 2008. Using Programme Theory to Evaluate Complicated and Complex Aspects of Interventions. *Evaluation*, 14(1), pp.29–48.
- Savedoff, W.D., Levine, R. & Birdsall, N., 2005. “*When will we ever learn? Recommendations to improve social development through enhanced impact evaluation.*,” Washington, DC. Available at: <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.483.4704&rep=rep1&type=pdf>.
- Smith, R., Mauremootoo, J. & Rassmann, K., 2012. *Ten years of Outcome Mapping adaptations & support*, Ottawa. Available at: http://www.outcomemapping.ca/download/10_years_of_OM.pdf.
- Snowden, D., 2016. SenseMaker® - Cognitive Edge. Available at: <http://cognitive-edge.com/sensemaker>.
- Stern, E. et al., 2012. *Broadening the Sharing the of Designs and Benefits of Trade Methods for Impact Evaluations*, London. Available at: <http://www.dfid.gov.uk/Documents/publications1/design-method-impact-eval.pdf>.
- White, H., 2009. *Some Reflections on Current Debates in Impact Evaluation*, Available at: http://www.3ieimpact.org/media/filer_public/2012/05/07/Working_Paper_1.pdf.
- WHO, 2015. *Capturing the difference we make: Community-based Rehabilitation Indicators Manual*, Geneva: WHO. Available at: http://apps.who.int/iris/bitstream/10665/199524/1/9789241509855_eng.pdf?ua=1.
- WHO, 2004. *CBR: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities. Joint position paper*, Geneva.
- WHO et al., 2010. *Community-based rehabilitation: CBR Guidelines*, Geneva. Available at: <http://www.who.int/disabilities/cbr/guidelines/en/>.
- WHO, 2002. *Innovative Care for Chronic Conditions*, Available at: <http://www.who.int/chp/knowledge/publications/iccreport/en/>.
- Wickenden, M. et al., 2016. Participatory Development of an Impact Evaluation Model and Toolkit for Community Based Rehabilitation (CBR) (in Uganda and Malawi). , p.63. Available at: <http://www.ucl.ac.uk/igh/research/a-z/participatory-development-impact-evaluation> [Accessed May 9, 2016].
- Wirz, S. & Thomas, M., 2002. Evaluation of community-based rehabilitation programmes: a search for appropriate indicators. *International journal of rehabilitation research*, 25(3), pp.163–171..
- World Bank, 2011. Impact evaluation. Available at: <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTPOVERTY/EXTISPMA/0,,menuPK:384336~pagePK:149018~piPK:149093~theSitePK:384329,00.html>.

About the authors

Erik Post is a medical doctor with an MSc in Health Policy, Planning and Financing. Currently he works for the Royal Tropical Institute as Senior Health Advisor, and has more than 20 years’ experience in Africa, Asia, and Latin America. Because of long field experience in leprosy work, he was involved in a variety of disability-oriented initiatives, such as medical rehabilitation, self-care, and livelihood support. Email: e.post@kit.nl

E. Post, H. Cornielje, K. Andrae, A. Maarse, M. Schneider and M. Wickenden. 2016.
Participatory inclusion evaluation: a flexible approach to building the evidence base on the impact of
community-based rehabilitation and inclusive development programmes.
Knowledge Management for Development Journal 11(2): 7-26
<http://journal.km4dev.org/>

Huib Cornielje is Director of Enablement Ltd and for 32 years has been active in the field of community-based rehabilitation. He is a coordinator and Senior Lecturer in Public Health at the University of Applied Sciences in Leiden, the Netherlands.

Email: h.cornielje@enablement.nl

Karen Andrae is an independent consultant working in the disability sector. She has experienced many (personal and organisational) transitions towards an increasingly inclusive and enabling approach to disability. She has particular expertise in monitoring, evaluation, and learning and interests in child-led and gender-responsive evaluations and impact.

Email: andrae.karen@gmail.com

Anneke Maarse is a Monitoring and Evaluation advisor, Double Loop Uganda. She is a physiotherapist with a Masters in Rural Sociology. She has grounded knowledge of disability and social inclusion, having acted as program manager of CBR, Inclusive Education, and Inclusive Vocational Training programs. She specialises in strengthening the capacity of individuals. Email: annkemaarse@hotmail.com

Marguerite Schneider is a Senior lecturer at the Alan J Flisher Centre for Public Mental Health, University of Cape Town. She is a social science researcher in disability and mental health with a focus on measurement. She works as a researcher in the field of public mental health in Cape Town and measurement of disability and mental health at a national and international level. Email: marguerite.schneider@uct.ac.za

Mary Wickenden is a senior research fellow in Disability and Development at the Institute for Global Health, University College London, UK. She is a medical anthropologist with interests in the lives, well-being and perspectives of disabled adults, children and their families living in low resources setting and in using participatory research methods to explore diverse aspects of disability and in evaluation of CBR and inclusion programmes.

Email: m.wickenden@ich.ucl.ac.uk

1 **Appendix: PIE evaluation framework**

Part 1. Impact by CBR component on the lives of People with Disabilities & their families: What impact is experienced by them or perceived by others? Assessment criteria/performance questions: What are positive and negative changes (IMPACTS) in the lives of PWD and their families in the past 3-5 years in relation to CBR components? (Include examples of impact on people with different types of disability, gender, age urban/ rural). Note consensus & divergent opinions among participants. What do people agree on, how and why?

Source of Information / Evaluation Criteria	People with Disabilities and their families	CBR Core Team	Strategic Partners in the CBR Network	Examples of evidence to look for: (these are not the only possibilities) Changes in
Impact - Health Empowerment Inclusion: Living Conditions	Individual Interviews and FGDs with: People with Disabilities, Parents, Carers, Children with disabilities	Individual interview with CBR manager FGD with CBR Core Team 5Cs Capability (V) Document review	FGDs with different Strategic Partners in the network	Access to medicine/ assistive devices/ services/ transport/ health information, physical & impairment specific access enabling: Attitudes & Knowledge of staff, recognition of/adaptation. Consequences of knowledge and behavior; Changes in living conditions self-esteem /changes in general <u>health status/impairment/functioning</u>
Impact - Education Empowerment Inclusion: Living conditions				Available services, school activities, clubs, non-formal learning; adapted learning materials; trained teachers & volunteers; attitudes of staff, enabling Changes in learners self-esteem & motivation, knowledge, skills, achievements, performance. education related costs eg; transport, WASH
Impact - Livelihood Empowerment Inclusion: Living conditions				Available/accessible financial services/support, IGA, micro loans, saving groups etc.Training/support; enabling: decision-making & control over income, choice self-esteem and motivation;, access to facilities, improved physical or emotional state
Impact - Social Empowerment: Inclusion: Living conditions				Participation in family and community events; interaction with community & family; awareness & respect by family/community. Self-esteem, decision-making and control over personal life, self-esteem and motivation; Changes in emotional state
Impact - Empowerment Empowerment: Inclusion: Living conditions:				Participation and representation in public life; Control over personal life Decision-making power, self-realization; self-esteem and confidence

2

Part 2. Other evaluation criteria related to organizational/structural aspects of the CBR programme which may explain positive or negative impacts and demonstrate contribution of the programme

Source of Information Evaluation Criteria	People with Disabilities and their families	CBR Core Team	Strategic Partners in the CBR Network	Examples of evidence to look for: Changes in
Relevance Are the right things going on?	Individual interviews FGDs with People with Disabilities Parents, Carers, Children	Individual interview with CBR manager FGD with CBR Core Team 5Cs Capability (I, III & V) Doc review	FGDs with different Strategic Partners in the network	Are the needs of disabled people/families being addressed by CBR programme and network? Is the CBR programme sufficiently adapted to the particular local context and conditions?
Efficiency Are the resources used wisely?		Individual interview with CBR manager 5C assessment (II, III)		Planning/MEL and auditing
Effectiveness Are things done well, equally for all? Quality: Accessibility: Coverage	Individual interviews FGDs with People with Disabilities Parents, Carers, Children	5C assessment (I & II) Document Review		Capacity building services (eg training/ coaching) to the CBR network, coordination of/collaboration, Quality of relationships, accessibility & adaptation examples Who is reached? By age/impairment/gender/location
Sustainability Will the service/support continue?		Individual Interview with CBR man 5C assessment (IV) Document review		Efforts at long term planning to, gain resources